TECHNOLOGY AND HANDICAPPED PEOPLE

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON
SCIENCE, RESEARCH AND TECHNOLOGY

OF THE

COMMITTEE ON
SCIENCE AND TECHNOLOGY
U.S. HOUSE OF REPRESENTATIVES

AND THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

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TECHNOLOGY AND HANDICAPPED PEOPLE

WEDNESDAY, SEPTEMBER 29, 1982

HOUSE OF REPRESENTATIVES, COMMITTEE ON SCIENCE AND TECHNOLOGY, SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY, AND THE U.S. SENATE, COMMITTEE ON LABOR AND HUMAN RESOURCES,

Washington, D.C.

The committees met, pursuant to call, at 9:10 a.m., in room 2318, Rayburn House Office Building, Hon. Doug Walgren (chairman of the House subcommittee) presiding.

Mr. WALGREN. I want to welcome everyone here on behalf of the subcommittee and tell you how much we appreciate your interest and that we are looking forward to these joint hearings with the Senate Committee on Labor and Human Resources, chaired, of course, by Senator Hatch from Utah. I would recognize Senator Hatch at this time to open the hearing.

Senator HATCH [presiding]. Thank you, Congressman Walgren. We appreciate your leadership in working with us on these hearings, and we are looking forward to them for they can be a great help in furthering the best interests of the handicapped.

I am pleased to be here today to participate with you at our joint House-Senate hearing on technology and handicapped people. Today technology touches nearly every dimension of the lives of disabled people. Modern technology has sometimes caused impairments but it also has provided a mechanism for reducing or eliminating handicapping conditions. Effective use of technology offers a most promising avenue to overcoming many physical and mental handicaps.

A recent survey conducted by the National Institute of Handicap Research reports that the U.S. Government spends about $66 million a year on technology research and development relating to disabilities. It also spends about $36 billion a year for income support of disabled people and appropriates over $2 billion on handicap education and rehabilitation. In spite of such expenditures, it is still rather apparent that gaps in services remain and that needs are not being fulfilled.

Considering these factors, the Senate Labor and Human Resources Committee requested the Office of Technology Assessment [OTA] to conduct a study of technology and handicapped people. The OTA study, which will be discussed today, concentrated on specific problems facing disabled people by examining the developments and the use of technology as a life-cycle process. This report points out that we are not adequately utilizing available technology nor sufficiently encouraging future research and development. In addition, it emphasizes that we fail to train an adequate number of personnel to help alleviate the problems.

By conducting hearings and conferences such as the one being held today, we can help solve the problem of inadequate dissemination and training. These sessions provide a setting in which to share ideas and to learn new techniques. Furthermore, meetings such as this hearing provide a forum to address the policy issues, to more clearly define solutions, to organize collectively and to provide critical information to Congress and the executive branch agencies.

It is through the efforts of witnesses here today and thousands of other dedicated experts that we can improve the quality of life for our 36 million handicapped citizens. Achieving these objectives will not only benefit our disabled and handicapped individuals but will be of tremendous value to society in general.

At this point I would like to put in the record, without objection, a statement by Senator Jennings Randolph for these hearings today.

[The prepared statement of Senator Randolph follows:]

STATEMENT BY SENATOR JENNINGS RANDOLPH, JOINT HEARING BY SENATE LABOR AND HUMAN RESOURCES COMMITTEE, AND HOUSE OF REPRESENTATIVES SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY, "REVIEW OF OFFICE OF TECHNOLOGY ASSESSMENT REPORT: TECHNOLOGY AND HANDICAPPED PEOPLE", WEDNESDAY, SEPTEMBER 29, 1982, 9:00 A.M., ROOM 2138 RAYBURN HOUSE OFFICE BUILDING

I AM PLEASED TO PARTICIPATE IN THE REVIEW OF THIS SIGNIFICANT REPORT BY THE OFFICE OF TECHNOLOGY ASSESSMENT. THIS IS A CONTINUATION OF THE WORK BEGUN BY THE SENATE SUBCOMMITTEE ON THE HANDICAPPED AND THE HOUSE SCIENCE AND TECHNOLOGY COMMITTEE IN NOVEMBER OF 1979 WHEN WE LOOKED INTO THE IMPACT OF TECHNOLOGY ON THE EDUCATION AND REHABILITATION OF THE HANDICAPPED. AMONG SIGNIFICANT DEVELOPMENTS IS LEGISLATION DESIGNED TO PROVIDE TAX INCENTIVES FOR DONATION OF COMPUTERS AND OTHER INFORMATION TECHNOLOGY: H. R. 5573 AND S. 2281. THIS WILL BE VERY

BENEFICIAL TO THE HANDICAPPED AND OTHER LEARNERS. THE FEDERAL GOVERNMENT SHOULD SUPPORT AND ENCOURAGE SOFTWARE DEVELOPMENT FOR THE NEW TECHNOLOGIES. PAST SUCCESS WITH EDUCATIONAL TELEVISION BY THE DEPARTMENT OF EDUCATION IS ONE EXCELLENT MODEL TO FOLLOW. THE QUALITY OF CHILDREN'S TELEVISION AND INSTRUCTIONAL TELEVISION HAS GREATLY INFLUENCED OUR EDUCATIONAL SYSTEM. I HOPE TO SEE SUCH PROGRAMS CONTINUED AND EXPANDED TO INCLUDE MICROCOMPUTERS AND OTHER NEW TECHNOLOGIES SUCH AS THE VIDEO DISK. THIS PROGRAM SHOULD SEEK TO MERGE PRIVATE SECTOR, SCHOOLS AND GOVERNMENT CAPITAL SO THAT COMPREHENSIVELY SOUND PROGRAMS MAY BE DEVELOPED THAT INCLUDE ALL CHILDREN.

I LOOK FORWARD TO SEEING THE FULL REPORT. IT IS MY HOPE THAT THE REPORT WILL INCLUDE ELABORATION ON THE IMPACT OF SIGNIFICANT GOVERNMENT PROGRAMS SUCH AS THE SCHOOL MEDIA AND LIBRARIES PROGRAMS, THE USE OF STATE

GRANT PROGRAMS SUCH AS THE PREVIOUS TITLE III, THE STATE AGENCY PROGRAMS FOR THE HANDICAPPED, AND NOW THE BLOCK GRANT PROGRAMS. HOW HAVE THESE PROGRAMS IMPACTED ON THE USES OF TECHNOLOGY IN THE SCHOOLS? ARE SCHOOLS AND STATES USING THE BLOCK GRANT MONEY TO SELECT TECHNOLOGY AS A PRIORITY? I ALSO WOULD HOPE TO FIND EARLY INDICATIONS OF THE IMPACT OF SECRETARY BELL'S INITIATIVE ON TECHNOLOGY. IT IS ESSENTIAL THAT THE DEPARTMENT OF EDUCATION TAKE THE LEAD IN DEVELOPING TECHNOLOGY PROGRAMS FOR EDUCATION. THEY CAN CONVENE THE NEEDED RESOURCES AND ACTIVITIES SO THAT THERE IS A COORDINATED APPROACH TO THIS ESSENTIAL ELEMENT IN OUR SOCIETY. MAJOR EFFORTS SHOULD BE:

(1) PREPARATION OF ALL PEOPLE TO LIVE IN A HIGH TECHNOLOGY WORLD.
(2) STAFF DEVELOPMENT OF EXISTING TEACHERS AND ADMINISTRATORS TO USE TECHNOLOGY EFFECTIVELY IN EDUCATION.

(3) COLLABORATIVE EFFORTS IN THE DESIGN, DEVELOPMENT AND DISTRIBUTION OF HIGH TECHNOLOGY FOR LEARNING.

(4) VALIDATION AND EVALUATION OF WHAT WORKS IN TECHNOLOGICAL TEACHING AND LEARNING.

I LOOK FORWARD WITH CONTINUED INTEREST TO THE ACTIVITIES WHICH WILL FOLLOW THIS REPORT.

Senator **Hatch**. I would like to mention the great pleasure it is for me to work with Senator Randolph, Senator Stafford, Senator Weicker, OTA, and others who have played such noble roles in helping the handicapped in our society. Mr. Gibbons, who of course is the head of our OTA, and I happen to be on the Office of Technology Assessment board of directors. I just want to express my pleasure working with him and mention the fine work he and his staff perform for us.

Doug, I am happy to participate with you. We will be happy to take your statement at this time.

Mr. **Walgren**. Thank you, Senator Hatch.

I want to say certainly at the outset we appreciate your interest on the Senate side. These issues are very compelling, but oftentimes—as with many issues in Congress—they get lost in the rush of legislative schedules. You have always been receptive to ideas that we have initiated on the House side, and I would just like to say that you are very much appreciated over here.

Senator **Hatch**. Thank you so much. That means so much to me.

Mr. **Walgren**. The purpose of the hearing, as Senator Hatch outlined, is to review the report of the Office of Technology Assessment, "Technology and Handicapped People." The report is the result of the initiative of the Senate Committee on Labor and Human Resources in 1980 and a request by that committee to look at those specific factors that affect the research, development, evaluation, financing, marketing, delivery, and the use of technologies directly related to disabled people.

The House Science and Technology Committee, of course, has had a continuing interest in exploring ways that our scientific and technological capability could be used to improve the quality of life of the disabled.

I know that all of us have had close relationships with people who have literally faced insurmountable obstacles in everyday living, and we really feel an obligation to use every resource at our disposal to try to make the changes that might make their lives a little bit better.

The hearing will focus on a major conclusion of the report, which is that technology's potential for aiding people who face these kinds of barriers and difficulties has not been adequately pursued or fulfilled. Although there are many problems that lie in the path of these developments, nonetheless looking back on the last several years, an objective observer would probably feel we could have done better and come farther than we have. It is my personal concern that every effort be made to use our scientific expertise to help those who face these difficulties, and I am sure that this concern is shared by the other members on this committee.

The report also contains a number of directions the Congress should consider, and the witnesses here this morning have been asked to address the issues covered by these suggestions. Again, to state the areas: Research, development, and evaluation of technologies; the degree of consumer participation in presently available methods; personnel issues; marketing and production issues; and financial barriers to the acquisition of technology and its use.

We are especially pleased to have Dr. John Gibbons, the Director of the Office of Technology Assessment, here who will give us an overview of the report.

We are under a substantial time constraint this morning because both the Senate and the House have heavy floor schedules, and I know Senator Hatch's time will be extremely limited. Also, we have a long list of witnesses. I hope it is understood that what we are doing here is building a hearing record from which we want to work in the future.

Our format is limited in such a way that we cannot explore every avenue and every question that is raised. Members and staff who are particularly interested will have a chance to read the transcript. We are interested in creating a comprehensive record here today which can then be developed further. We hope out of that will come something very good.

I would also like to announce that there will be an exhibit of technology to aid the disabled this afternoon from 1 to 6:30 p.m. in room 1202 of the Dirksen Senate Office Building, and I recommend it to everyone. The exhibit is sponsored by the Capitol Conference on Technology and Handicapped People. It is gratifying to see the things that are being done now and also to envision the potential technology of the future.

At this point I would like to insert in the record a statement by Margaret Heckler, the ranking minority member of the subcommittee.

[Opening statements by Congressman Walgren and Congresswoman Heckler follow:]

OPENING REMARKS BY CHAIRMAN DOUG WALGREN
HEARING TO REVIEW THE OFFICE OF TECHNOLOGY REPORT:
TECHNOLOGY AND HANDICAPPED PEOPLE
SEPTEMBER 29, 1982

GOOD MORNING. IT IS INDEED A PLEASURE TO CO-CHAIR THIS JOINT HEARING WITH THE DISTINGUISHED SENATOR FROM UTAH, ORRIN G. HATCH, CHAIRMAN OF THE SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES.

THE PURPOSE OF THE HEARING IS TO REVIEW THE OFFICE OF TECHNOLOGY ASSESSMENT REPORT, TECHNOLOGY AND HANDICAPPED PEOPLE. THE REPORT IS THE RESULT OF A REQUEST BY THE SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES IN 1980 FOR OTA TO LOOK AT THOSE SPECIFIC FACTORS THAT AFFECT THE RESEARCH, DEVELOPMENT, EVALUATION, FINANCING, MARKETING, DELIVERY, AND USE OF TECHNOLOGIES DIRECTLY RELATED TO DISABLED PEOPLE.

THE HOUSE SCIENCE AND TECHNOLOGY COMMITTEE HAS HAD A CONTINUING INTEREST IN EXPLORING THE WAYS THAT OUR SCIENTIFIC AND TECHNOLOGICAL RESOURCES CAN BE UTILIZED TO IMPROVE THE QUALITY OF LIFE OF THE DISABLED.

THE HEARING WILL FOCUS ON A MAJOR CONCLUSION OF THE REPORT WHICH IS THAT TECHNOLOGY'S GREAT POTENTIAL FOR AIDING DISABLED PEOPLE HAS

NOT BEEN FULFILLED, AND ALTHOUGH THERE ARE MANY PROBLEMS RELATED TO THE DEVELOPMENT AND DISTRIBUTION OF THIS TECHNOLOGY, MANY OF THEM COULD ALSO BE AVOIDED OR LESSENED. IT IS MY PERSONAL CONCERN THAT EVERY EFFORT BE MADE TO USE THIS NATION'S SCIENTIFIC AND TECHNOLOGICAL EXPERTISE TO HELP THE DISABLED TO LIVE MORE FULFILLING AND PRODUCTIVE LIVES.

THE OTA REPORT ALSO CONTAINS POLICY OPTIONS FOR CONGRESSSIONAL CONSIDERATION. THE WITNESSES HERE THIS MORNING HAVE BEEN ASKED TO ADDRESS THE ISSUES COVERED BY THESE POLICY OPTIONS, NAMELY: RESEARCH, DEVELOPMENT, AND EVALUATION OF TECHNOLOGIES; CONSUMER PARTICIPATION; PERSONNEL ISSUES; MARKETING AND PRODUCTION; AND FINANCIAL BARRIERS TO TECHNOLOGY ACQUISITION OR USE.

WE ARE ESPECIALLY PLEASED TO HAVE DR. JOHN GIBBONS, THE DIRECTOR OF THE OFFICE OF TECHNOLOGY ASSESSMENT HERE TO GIVE AN OVERVIEW OF THE REPORT, AND I WOULD LIKE TO COMMEND THAT OFFICE ON THEIR EFFORTS.

WE ARE UNDER A TIME CONSTRAINT THIS MORNING DUE TO A VERY HEAVY FLOOR SCHEDULE; THEREFORE, I WOULD ASK THAT MEMBERS BE SPARING IN THEIR QUESTIONS. IF MEMBERS HAVE QUESTIONS REQUIRING LONG ANSWERS WE WILL SUBMIT THE QUESTIONS TO THE WITNESSES IN WRITING FOR THE RECORD.

I WOULD ALSO LIKE TO ANNOUNCE AT THIS TIME THAT AN EXHIBIT OF TECHNOLOGY TO AID THE DISABLED WILL BE ON VIEW FROM 1:00 TO 6:30 P.M. THIS AFTERNOON IN ROOM 1202 DIRKSEN SENATE OFFICE BUILDING. THIS EXHIBIT, SPONSORED BY THE CAPITOL CONFERENCE ON TECHNOLOGY AND HANDICAPPED PEOPLE, PROVIDES AN EXCELLENT OPPORTUNITY TO SEE THE END RESULTS OF TECHNOLOGICAL EXPERTISE.

PREPARED STATEMENT OF HON. MARGARET M. HECKLER

Thank you, Mr. Chairman. I, too, am very pleased with today's hearing. I am, pleased primarily because in the application of technology to the needs of the disabled we see a very human and compassionate side of technology. In addition, it is always a pleasure to join with our Senate colleagues on matters of mutual concern.

The Senate Committee on Labor and Human Resources is to be complimented for their leadership in asking the Office of Technology Assessment to prepare the study before us today.

Our schedule is extremely tight today between the number of witnesses and the pace of action on the House floor so I will keep my comments brief.

The OTA report makes some important observations that I think deserve the specific attention of today's witnesses and certainly of both committees. The most basic observation is that the current structure of disability related R&D, evaluation, diffusion, and marketing "is capable of, and has produced, important contributions to disabled and non-disabled people. It definitely has had success stories, stories that frequently have been due to the dedicated effort of individuals rather than to the thoughtful application of effective governmental or private systems of development and diffusion. . . . the system is, or could be, capable of a great deal more."

In other words, we aren't getting our money's worth out of what already exists, not by a long shot.

Why not?

The authors cite a White House study for some of the reasons, which include ". . . inattention to the definition of discrete, project oriented tasks, by the lack of a suitable basic science to support the managerial decision processes required, by a scarcity of people trained and educated in the application of engineering principles to the handicapped, and by the high cost of technical failures induced by non-perception of real needs."

The authors themselves stated what they perceived to be a major problem. "The Federal Government," they said, "does not have consistent, formal mechanisms in place to link research investment to the production and distribution needs of the marketplace."

This inefficient use of the resources at hand is a major stumbling block to the effective utilization of increasingly scarce resources. The system's inefficiency is so significant that the report states, ". . . it should be recognized that more money will not in itself solve all problems."

This is, I think, a very important point. Not because any of my colleagues would not like to see more money in this area, but because with enormous federal deficits ahead of us we will not have any money to give! It is vitally important, then, that we are able to get as much out of the system as is possible.

Let me conclude my remarks, Mr. Chairman, by summarizing what I feel are some very wise suggestions offered by the report.

A strengthening of public-private sector partnerships in marketing new technologies for disabled people is recommended. This will mean the developing of strategies to coordinate information on the delivery and use of technology for the disabled.

Of critical importance is the participation of disabled individuals in the actual design and development of new technologies in order to reduce the current emphasis on "fancy" technologies that often represent the desires of the researcher more than the practical needs of the truly disabled.

Mr. Chairman, the report makes it quite clear that we are not getting the kind of benefits from Federal R&D for the handicapped that are currently available. I think the committee should take this message from the Office of Technology Assessment and hold hearings early in the next session of Congress in order to develop a focused strategy for the application of technology for the disabled.

Mr. WALGREN. I would like at this time to recognize the presence of the former chairman of this subcommittee, George Brown, who has maintained a continuing interest in the area of research to aid the handicapped, and give him an opportunity for any opening comment he might have.

Mr. BROWN. Mr. Chairman, thank you very much. I will insert an opening statement in the record at this point with your permission.

[The opening statement of Congressman Brown follows:]

Congressman George Brown
September 29, 1982

OPENING STATEMENT FOR HEARINGS ON TECHNOLOGY AND THE HANDICAPPED

Mr. Chairman, I would like to commend you and this subcommittee for holding these hearings today on such a neglected, but vital topic. I know that my own interest in this area began in the sixties when I served on the Veterans Affairs Committee. The Chairman of the Committee at that time, Olin "Tiger" Teague was himself a disabled veteran. Tiger made great contributions. First in the Veterans Affairs Committee, which he chaired for many years; then in the Science Committee, which he also chaired. I had the honor of serving with and for him on both committees where we shared a special concern to effectively utilize science and technology to meet the needs of those with some special disabling situation.

I, myself, had the honor of serving as Chairman of the Task Force on the Handicapped, which merged into this subcommittee. During this time, I have seen numerous technological advances. In the last decade we have been successful to a certain degree at taking technology, which may have been developed for a particular reason, and transferring it to an application which may be widely different from the original intentions. A prime example is the work of the space program. The technological applications originally designed for NASA have been instrumental in rehabilitation engineering. This transfer has ranged from rechargeable pacemakers to improved prosthetic limbs to more effective early-warning diagnostic tools.

While research and development advances are essential, the evaluation, diffusion, and marketing activities of technology for the handicapped must be integrated with other services. An innovation still on the shelf because of inadequate delivery processes does little good to the ultimate consumer--the handicapped individual.

It is also essential that we develop a cohesive federal policy, rather than the fragmented and sometimes contradictory one we have now, because the number of disabled are increasing and will likely continue to do so. The public as a whole has begun to recognize that there is a marked increase in partial disability during our life cycles--traumatic injury at any age and physical and mental deterioration among the elderly. The typical American is now living so long on the average that engineering systems of the body--the pumps, filters, fluid flow channels, structures, motor bearings, information paths, and control centers--deteriorate. This relation to handicapping conditions should not be ignored, particularly in light of the fact that it is estimated that by the year 2050 Americans 65 years of age and over may number 40 million or 16% of the population.

If we do not take the time now to formulate a cohesive policy which will encourage technological advances as well as facilitate their marketing, we will find ourselves continuing the trend of forced dependence. Already the United States government spends about $36 billion each year in income support for the handicapped, but only allots a mere $66 million for research and development in technologies which might make these individuals productive.

I welcome the examination of alternatives to this trend, and again thank the Chairman for his foresightedness in this area.

Mr. BROWN. I am very grateful that you and Senator Hatch have chosen to take this important initiative. It carries on a tradition of concern in the Science Committee that goes back at least a generation, and I am delighted to see it carried on in such a forceful way.

Thank you.

Senator HATCH. Thank you, George. It is certainly nice to be over here in the upper body today and being able to hold these hearings. We appreciate the work you do on OTA, and it is just great to have you here.

I really enjoy working with these Members of the House. They are dedicated leaders in this area, and we appreciate it.

Our first witness for today will be Dr. John H. Gibbons. He directs the Congressional Office of Technology Assessment, known as OTA in Washington parlance, and referred to by some as the congressional think tank.

Congress authorized the agency in 1972 to provide itself with a source of information that is nonpartisan, expert, objective, and anticipatory. OTA prepares comprehensive analyses of a broad spectrum of important, complex, and often controversial issues involving technology. Subjects of recent studies range from Soviet energy availability and applied genetics to MX missile basing and national information systems.

Dr. Gibbons was appointed OTA Director in 1979. He is a nationally recognized scientist, an expert in energy and environmental issues, and a man with a deep interest and concern regarding the impacts of technology on society and what these impacts imply for the formulation of sound public policy.

Prior to his appointment at OTA, Dr. Gibbons directed the Energy Resources and Environment Center at the University of Tennessee, and was a member of a variety of national advisory and study groups.

In 1973 he was called to Washington to organize the first energy conservation activities for the Federal Government. He served until the Federal Energy Administration was established in 1974, and received FEA's Distinguished Service Award for his work.

Jack Gibbons is a native of Virginia. He earned a B.S. in mathematics and chemistry from Randolph-Macon College, and a Ph. D. in physics from Duke University.

Dr. Gibbons spent 19 years with the Oak Ridge National Laboratory, beginning as a research physicist and rising to direct its program of studies on energy and materials conservation, and on the environmental consequences of power production.

In recognition of his scientific contributions, Dr. Gibbons has been elected a fellow of the American Physical Society and the American Association for the Advancement of Science. His publications range from experimental nuclear physics to, most recently, a book on the influence of energy price and technology on future energy demand.

He is an outdoorsman and enjoys mountain climbing, hiking, tennis, exploring caves, and farming, and of course has a wonderful family here in Washington with him.

Dr. Gibbons, we are happy to have you with us. You are accompanied by Clyde J. Behney, the project director for the study.

Clyde, we are grateful to have you with us as well. We are looking forward to your report on your activities.

I will conduct the hearings up through the first panel, and then of course since these are joint hearings and we are co-conducting them, I will turn the rest of the hearing over to my good friend and colleague Congressman Walgren, who will continue the hearings from that point.

STATEMENT OF JOHN H. GIBBONS, DIRECTOR, OFFICE OF TECHNOLOGY ASSESSMENT, ACCOMPANIED BY CLYDE J. BEHNEY, PROJECT DIRECTOR FOR THE STUDY

Dr. GIBBONS. Senator Hatch, Chairman Walgren, I am very pleased to be here this morning to summarize the OTA study, and I am pleased to bring with me Clyde Behney, who directed that project at OTA and is now program manager for our program in health.

We were asked by your committee, Senator, the Committee on Labor and Human Resources, to examine how technologies for disabilities are developed, evaluated, and put to use, and then to identify any problems or missed opportunities that are related to that process.

The study also identified policy options for congressional consideration. With your permission I would like to submit a copy of the summary of that study for the record.

Senator HATCH. Without objection, we will enter that into the record.

[The information mentioned above may be seen in committee files.]

Dr. GIBBONS. The Federal Government is deeply involved in programs that affect the use of technologies for disabilities. The programs cover research and development, marketing, financing of technologies, civil rights and their enforcement, employment, transportation, health care, income maintenance, independent living, and many other aspects of life.

Concerns have been raised about the consistency of objectives of these programs, conflicting incentives, and lack of appropriate distribution of technologies.

Many people have modest impairments, and others are significantly disabled in their ability to perform one or more of life's important functions. These limitations either are present from birth or they can occur from injury, disease or aging. I had a sore back last week, and I think aging is catching up with me.

Senator HATCH. I join you in that.

Dr. GIBBONS. Whether an impairment, however, becomes a disability—that is, a limited basic human function—depends on many things, including technology. Whether a disability in turn becomes a handicap depends on the interaction of the disabled person with the physical and social environments surrounding that person, and many other factors as well. And, again, technology is one of those factors.

Some technology, especially medical technology such as knee implants or eyeglasses, can eliminate or reduce impairments and keep them from becoming disabilities. Other technologies are used extensively to prevent disabilities from becoming handicaps by, for example, making transportation systems and accommodations accessible.

Disability technology may be very complex, such as a voice-activated powered wheelchair, or simple, such as special utensil attachments. Disability technology is used to facilitate what is called mainstreaming in education, to prepare disabled people for employment, to adapt job sites to the capabilities of disabled persons, and to create manageable home environments.

Technology for disabled people plays the role of improving the compatibility between individuals on the one hand and their environment on the other. By making a distinction between disability and handicaps, OTA has recognized the necessity of studying both the individuals and the environments in which they function.

The key to appropriate development and use of technologies is finding the compromise between, first of all, the needs, desires, and capabilities of users and other relevant parties, and second, the costs, risks, and benefits of technology. Such compromise might be simple when for example, deciding to prescribe or wear eyeglasses. However, some compromises are far more complicated. For example, whether or not to consider a myoelectric limb for a person. In such cases, an explicit framework for analyzing technical alternatives becomes very important.

A major conclusion, gentlemen, of the OTA study is that despite the existence of numerous important technical problems and opportunities related to developing technologies, the more serious issues are social and economic ones rather than the technologic issues.

I would like to spend a few moments now summarizing other findings of the study.

As the committee knows, the U.S. Government spends $66 million a year on R&D related to technologies for disability. However, the U.S. Government also spends more than 500 times that amount—about $36 billion—each year just to support the income of disabled people. Thus, its R&D expenditures in this area represent only 0.2 percent of its transfer payments. When other costs related to disability are included, such as health care, the percentage becomes even smaller.

Despite problems, disability-related R&D is characterized by innovation. Given sufficient funding and an effective organization of efforts, the predicted explosion in relevant technologies could become reality. Advances in solid-state electronics, other communications/information developments, new alloys, microcomputer-aided movement—for example, of artificial limbs—and biomedical knowledge, including neurochemistry, are already producing dramatic improvements as well as new possibilities. The future may see an acceleration of technological contributions. Some advances, such as writing aids for physically disabled children, may have great value; others may turn out to be useless. Most important, though, is planning and identifying the appropriate ways to evaluate, distribute, and use the breakthroughs.

Evaluation of technologies should be an integral part of the R&D and marketing process. For disability-related technologies, however, OTA found inadequate attention is being given to evaluation. This finding is especially true for criteria such as repairability, convenience, cost, consumer satisfaction, funding or reimbursement status and potential, and cost-effectiveness. Evaluation becomes particularly crucial in view of the possibility of a significant increase in the number of technological advances, such as in the area of communications devices or mobility aids. Unfortunately, this area of technology has not had a tradition of evaluation, and is presently subject to very low funding for the evaluation process.

There are relatively few examples of successful Federal efforts to bring a product developed under a Federal R&D program to private manufacturers for mass marketing and distribution. The Veterans' Administration, the National Aeronautics and Space Administration, and the National Institute of Handicapped Research are lead agencies for the successes that have occurred. The reasons for the lack of success include several that arise from the specific characteristics of the disability-related market: The disability population is ill-defined; the economic status of users is often far below the average; disability-related technologies often do not appear viable from a strictly market perspective, resulting in a lack of private interest in their production; product liability is often perceived by manufacturers to be a problem; and, especially, the systems for third-party reimbursement of devices sometimes discourage the marketing of certain types of technologies.

I should add it is important to point out that third-party reimbursement such as medicare is also one of the largest sources of funds for disability technology.

In addition, many of the factors that hinder the successful commercial application of Government-funded research in any technological area also apply in the disability area. For example, Government support is often given for research and development of technologies that are complex and expensive, making them less competitive in the marketplace. Also, the public patent status of Government-sponsored technologies can be a disincentive to their later commercial development.

The use of technologies by disabled people depends primarily, but certainly not entirely, on their eligibility for public and nonpublic programs that provide the devices and related services. This is partly because many disabled people have lower than average earnings, and partly because the programs are the primary source of information on available technologies. Through their affiliation with these programs and services, users either receive devices and services directly, have them financed, or learn about them. The programs consist mainly of: First, income maintenance, second, health and medical care, third, social services, fourth, educational services, and fifth, vocational rehabilitation and independent living.

OTA found that the current system of disability-related research, development, evaluation, diffusion, and use suffers from a number of significant weaknesses. The system could be capable of providing a great deal more service, even with existing levels of funds. For example, inadequate attention is being paid to the concept of appropriate technology; that is, finding a compromise fit between the device and the user. Analytical methods for determining and attaining the proper match of technology and user need to be developed and applied over the lifetime of the disabled person. In addition, information on available technologies is often fragmented, so that disabled persons, rehabilitation workers, insurance companies, and other individuals and groups may have difficulty locating needed data. Strengthened information dissemination is urgently needed.

Providing disabled individuals with the advantages offered by technology requires the resolution of several policy issues. Federal policies on financing and R&D of technologies would be greatly improved if they encouraged criteria for devices such as rate of obsolescence, ease of maintenance, ease of actual procurement by the user, and users' preferences. A disabled person might then have a better basis, for example, for selecting a manual wheelchair over a power wheelchair.

The OTA report presents a series of issue areas and related options, which will be considered at the Capitol Conference on Technology and Handicapped People. I would be pleased to submit a copy of the issues and options chapter from the report for the record and mention to you only the issue areas that the options address.

Senator HATCH. Without objection, the information will be included in the record.

[The information follows:]

CHAPTER 12 OF THE REPORT

"TECHNOLOGY AND HANDICAPPED PEOPLE"

OFFICE OF TECHNOLOGY ASSESSMENT

CONGRESS OF THE UNITED STATES

SUBMITTED FOR THE RECORD

IN CONJUNCTION WITH THE STATEMENT OF

JOHN H. GIBBONS, DIRECTOR

OFFICE OF TECHNOLOGY ASSESSMENT

U.S. CONGRESS

BEFORE THE

SUBCOMMITTEE ON RESEARCH, SCIENCE AND TECHNOLOGY

COMMITTEE ON SCIENCE AND TECHNOLOGY

UNITED STATES HOUSE OF REPRESENTATIVES

AND THE

COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

ON

TECHNOLOGY AND HANDICAPPED PEOPLE

SEPTEMBER 29, 1982

12.

Policy Options

A large number of factors affect the success of technological applications in the area of disabilities. Among the most influential factors are Federal policies. This chapter discusses possible changes in those policies. Some involve legislative changes. Others are oriented to actions of the executive branch, but would involve congressional oversight or encouragement. None of them are recommendations: OTA does not recommend any particular course of action. They are options for congressional consideration. The options are not, for the most part, mutually exclusive. The adoption of one option within a category does not necessarily mean that the others are inapplicable. On the contrary, better effect can often be had by a careful combination of options.

Many of the generic problems that exist in this area range from a lack of financial incentives for manufacturers to produce devices for disabled people, to a lack of evaluation and evaluation criteria, to inadequate information transfer systems. These types of problems could be alleviated by a concerted effort involving public agencies, private organizations, and consumer and citizen participation. However, many of the other problems are so deeply rooted in complex financial circumstances that it might take substantial changes in reimbursement policies and in the public-private sector relationship to bring about significant improvements.

Some of the problems are based in social and psychological attitudes that cannot be changed simply by appropriating more money or by reorganizing Federal agencies. Federal policies can have some effect in changing attitudes, but any substantial change may depend as much or more on disabled persons themselves. Opportunities for changing attitudes, however, can be enhanced by Federal policies and administration that assure employment and education activities, thus changing the amount of interaction that takes place between disabled people and nondisabled persons.

The options below are presented by issue areas. Despite this division, which is for the purposes of presentation, it is important to bear in mind the extremely important interactions that occur both among the stages in the lifecycle of technology and between technical issues and resource or social issues.

PRODUCTION, MARKETING, AND DIFFUSION OF DISABILITY-RELATED TECHNOLOGIES

ISSUE 1

How can the Federal Government increase the probability that technologies will reach the people who need and desire them?

In as many cases as possible, commercial viability should be one of the goals sought in technology developed using Federal funds. A critical issue is how to alter the currently inadequate state of marketing efforts and processes.

As discussed in chapters 8 and 9, one of the most critical and yet currently inadequate stages in the lifecycle of technologies for disabled people is the movement of technologies from development to use. Production and distribution are weak links in the process of technology development and diffusion. *The production, marketing, and diffusion of technologies are steps that are most often appropriate private sector activities, and yet a number of factors work against that sector's willingness and ability to engage in those activities.* Research and development (R&D) organizations have typically placed a low priority on production, marketing, and diffusion activities. The National Aeronautics and Space Administration's (NASA's) activities in technology transfer illustrate an exception. In general, however, the ultimate commercial production and distribution of technologies being developed with Federal funds have not been given sufficient attention.

There are several market-oriented factors that work against the involvement of the private sector. The difficulty in projecting the markets for disability-related technologies increases the risks of a commercial venture, as do the often small populations in question. Also, disabled individuals traditionally have had low average earnings or funds at their disposal.* The financing and reimbursement policies of the Federal Government and the States also contribute to the uncertainties of the marketplace for a firm considering the production of a technology. (this problem is covered under the option area below on financial barriers to the acquisition of technology.)

OTA finds that the key problems in the production and marketing area are the following: 1) lack of attention to production and marketing during the R&D and evaluation stages (this is covered under the option area below on research, development, and evaluation of technologies); 2) absence of adequate data on potential markets and on the needs, desires, and capabilities of people in those markets; 3) lack of organizations that could provide such data in the form needed by potential production and marketing firms; 4) greater than average risks related to entering the disability market; 5) Federal fiscal and regulatory policies that do little to reduce such risks; and 6) inadequate mechanisms for funding the purchase of devices (especially those seen as "not medically necessary").

OPTION 1A

Congress could amend current legislation to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies.

This option would require a substantial effort on the part of Congress to identify and review relevant sections of many statutes and regulations. Amending fiscal, monetary, and regulatory policy to create a consistent package of incentives will not be an easy task, nor, perhaps, one that can be accomplished without much compromise.

Nevertheless, this option recognizes the current confusing and often detrimental collection of competing incentives set up by such laws. It implicitly is based on several ideas: 1) that a great many technologies, though certainly not all, could be serving far more people than currently; 2) that some, perhaps many, technologies' development and subsequent distribution depends less on further research than on the willingness and ability of private industry to develop, produce, and market them; 3) that policies of the Government greatly affect private industry's willingness and ability to produce and market these technologies; and 4) that current legislation and regulations do not create adequate positive incentives for those firms to do so.

This option is more applicable to hard technologies such as devices than to soft technologies such as counseling methods, planning or educational techniques, or service delivery systems. Nevertheless, firms or other organizations that might potentially develop and market soft technologies should also benefit from any changes in fiscal or regulatory incentives.

Fiscal incentives are created by policies that reduce the financial uncertainties associated with risk-taking in the disability field. Their objective would be to allow private investors and firms to make more reliable estimates of potential returns on investment *and* to increase the probability of a satisfactory return on investment. The principal type of policy that creates fiscal incentives is taxation policy.

Regulatory incentives seek to accomplish the same objectives as fiscal incentives but do so through methods less directly connected to financial factors. Patent and licensing policies are examples of areas where regulatory incentives might be created. Another example would be changes in the penalties for noncompliance with Federal regulations regarding the hiring of disabled people or the provision of appropriate technologies to disabled people. This type of incentive would increase the demand—and therefore the potential market—for technologies, as well as more fully utilize the skills of professionals and technicians who happen to have disabilities.

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*As indicated earlier, figures on the average earnings of disabled people may be deceptively low due to the fact that many such estimates are derived from people in assistance programs. Disabled people who are not enrolled in such programs are often not counted, and, presumably, these people have higher earnings than the estimates for the average disabled person. The perception of earnings levels of disabled people, however, are still based on such possibly deceptive average estimates and therefore may negatively affect the willingness of firms to take marketing risks.

A full study of the possible incentives and their potential interactions and results might be necessary before this option could be implemented. The following potential fiscal and regulatory mechanisms for creating incentives should be included in such a study:

- accelerated tax writeoff of equipment and other capital investments;
- allow individual tax deductions for devices that are not covered by insurance or other payment programs;
- expanded efforts in guaranteeing markets to potential producers of a technology (e.g., through the Veteran's Administration (VA), vocational rehabilitation programs, or education assistance programs);
- modified capital gains taxes on investments in firms designated as producers of disability-related technologies;
- extended carryover of losses for designated firms;
- tax credits against profits for designated small businesses for a specified number of years;
- other tax reduction policies for investors or firms engaging in the production or delivery of relevant technologies;
- strengthening and clarifying of rules for compliance with Federal laws concerning nondiscrimination in hiring, employment, etc., and concerning the reasonable accommodations that must be made by employers, schools, etc., to allow the participation of disabled people (this mechanism acts to increase the productivity and well-being of disabled people and to increase their ability to afford technologies, thereby increasing potential markets);
- facilitating the awarding of grants and contracts to small, profit-seeking businesses for the development and testing of relevant technologies;
- cooperation with State and local governments in providing low-interest-rate loans, direct subsidies, or guaranteed markets/purchases for small firms;
- expanded coverage under Federal health insurance and service provision programs to include those technologies which, though not viewed as strictly "medically necessary," increase the capacity of disabled persons to function more independently and productively;
- modification of the present patent system to allow small firms (which make up the majority of firms in this area) to secure patents in less time and at less expense (e.g., through Federal subsidies for patent expenses); and
- clarification and greater standardization of Federal policies in regard to the granting (to firms that might produce needed technologies) of exclusive or nonexclusive licenses to Federal patents.

In designing a package of fiscal and regulatory incentives, Congress should consider a range of factors that play an important role in the willingness and ability of organizations to produce and market technologies. Some of these factors are:

- the difficulty of obtaining venture or risk capital for the production of a technology whose future success is subject to the higher than average uncertainties of the disability-related market;
- uncertainty about patent rights for products developed with Government funds;
- uncertainty about whether the technology will be covered by insurance companies or Government programs;
- the possibility of product liability costs;
- the difficulties of "selling" the merits of a product to intermediaries (e.g., insurance companies, the VA school districts, Medicare) as well as direct users; and
- the need to spend more time and funds than the average on market analysis, prototype development and testing, and training of

consumers and others in the maintenance and use of the product.

The implementation of this option would have both benefits and costs, all of which would share some of the uncertainty inherent in this area. On the benefit side, revenues to the Federal Government might be increased as a result of the larger corporate taxes paid by firms and the increased taxes paid by disabled people who would receive technologies that allow them to lead more productive lives. Revenues would be reduced by the amounts of any tax reductions embodied in the fiscal incentive structure. Federal costs would be diminished by the reduction in funds spent on income transfer, health insurance payments, etc., due to disabled people's being able to leave Federal and State programs. A prime social benefit of changes in incentives, however, is one that would be very difficult (perhaps impossible) to put into dollar terms—i.e., the increases in well-being (psychological and economic) of the disabled people who would benefit from the distribution of helpful technologies.

OPTION 1B

Congress could legislatively charter a private organization to provide marketing and production-related services to both the private and the public sectors.[*]

The Federal Government, through Congress, has occasionally granted an official Federal charter to an organization when Congress has felt that such an organization would serve the public welfare. An example is the charter granted to the National Academy of Sciences. Chartering can be accomplished by an act of incorporation passed by Congress and signed by the President. A federally chartered organization, though not a Federal agency, is or may be considered a public organization for such things as compliance with civil rights legislation.

The initial funds and the operating expenses for such an organization would come from the nonpublic sector, with perhaps a small startup grant from the Government. After startup, however, the organization would be expected to operate on its own revenues. For purposes of taxation, it would be considered a nonprofit organization. An organization of this type would be eligible to receive funds from any source, including Government agencies, philanthropic foundations, voluntary agencies, industry, estates, and gifts or donations.

The goal of the organization would be to provide technical assistance, analysis, and other services related to the production, marketing, and diffusion of disability-related technologies. In return for fees, it could perform marketing surveys and help put together market strategies for private firms who are considering entering a new product on the market. It could serve as a liaison between firms or Government agencies and ultimate consumers. It could develop and manage demographic and product data sets.

The success of this type of organization might depend on three items: the quality and reputation of its staff, its ability to deliver helpful services, and its ability to cope with what might be a large demand for its services while it is still young and growing. One of the goals of a Federal charter, in fact, would be to give the organization the prestige to attract qualified staff members. The organization would be eligible to receive Federal and other governmental grants and contracts. The National Institute of Handicapped Research (NIHR), its rehabilitation engineering centers, the Rehabilitation Services Administration (RSA), VA, NASA, the National Science Foundation, the National Institutes of Health (NIH), and other agencies should be encouraged to use the organization *as appropriate*. An organization of this type must be very careful to represent itself as being able to deliver only those services that it can (which will change as the organization grows and builds expertise and data) and only within the time frame that it can handle.

The proposed organization might be able to do technology evaluations, either directly or by managing evaluation projects that others are actually carrying out. However, this function should be added to the list of the organization's activities only if it can be clearly and cleanly separated from the functions of assisting the marketing of products. Conflicts of interest could prove very harmful to the organization and its goals.

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[*] Much of the discussion under options 1B and 1C were suggested by and drawn from a paper by Tom Joe, "The Application of Technology for the Disabled: A Joint Public-Private Venture" (Center for the Study of Social Policy, University of Chicago, 1981).

One potential advantage of the proposed organization is that it is designed to carry out an important and currently inadequately performed function; another is that it is located in the nonpublic sector. Potential disadvantages lie in the possibility of conflict of interest and in the nature of the tasks assigned to the organization. In order to consistently attract private and public funds, the organization would have to deliver valuable but extremely difficult services.

One crucial point is that the proposed organization should have broad representation of many different groups and constituencies. Consumers and marketing and production experts would be essential. Demographers, taxation and fiscal experts, the general public, analytical experts, technologists and researchers would also be very important to the organization's success.

Canada has an organization similar to the one of this option. Technical Aids and Systems for the Handicapped, Inc. (TASH) was established as a nonprofit corporation by the Canadian National Research Council and the Canadian Rehabilitation Council for the Disabled. It provides marketing, supply, and maintenance services, especially for devices that are not widely available. The experience of TASH should be examined closely before any decision about establishing a similar domestic organization is made.

OPTION 1C

Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and the public sectors.

This option has goals similar to those of the previous option and seeks to accomplish them through somewhat similar means. The principal difference between the two options is the legal authority under which the proposed organization would operate. The organization proposed in the previous option would be considered a private corporation for most purposes; that proposed in this option would be as quasi-governmental entity. the entity could be a nonprofit corporation existing to serve the public good by acting much as a private sector organization. Analogous organizations are the Overseas Private Investment Corporation, the Tennessee Valley Authority, and the Federal National Mortgage Association.

An example of a similar organization is the Communications Satellite Corp. (COMSAT). COMSAT is a private firm, owned by its shareholders, with a board of directors who are not officials of the Government. It is not a public corporation, nor has it been granted a Federal charter of incorporation. Three of COMSAT's directors, however, are nominated by the President and confirmed by the Senate. Even though COMSAT is a wholly private organization, it is considered to be performing a service that is in the best interests of the public and has therefore been given special status (e.g., it is by Federal statute designated the organization that represents the United States in the International Telecommunication Satellite Organization). COMSAT, therefore, illustrates another possible method of aiding the establishment of an organization to provide needed services.

The goal of setting up a public-private corporation such as that proposed in this option is to support the performance of services deemed to be in the broad public interest through the use of primarily private funding and private sector managerial techniques. One possible and potentially very important element of such a corporation's mandate could be the inclusion of a formal requirement that the corporation subcontract with consumer groups or a single consumer organization for the testing and evaluation of technologies. The consumer groups could be chosen competitively, on the basis of criteria established by, for example, the board of directors of the corporation. The corporation need not be limited to consumer groups for its subcontracting, but such groups should play a significant role in its operations. As in the previous option, the corporation should only be allowed to perform evaluation services where no conflicts of interest exist.

Because of the possibility of conflicts of interest, Congress may wish to establish two separate public-private corporations (or two separate chartered organizations) to perform the two functions of providing marketing and production-related services, and evaluating technologies and disseminating the results. If so, it would be desirable to have some mechanism to coordinate the activities of the two organizations (e.g., a joint board of directors). It might also be desirable for the two to share a data system, both to ensure compatibility and standardization of information and to avoid much potential duplication.

OPTION 1D

Congress could mandate the collection of market-related demographic data by an interagency group led by the Bureau of the Census.

This option would be an attempt to reduce some of the uncertainty that accompanies decisions to develop or market products to be used by disabled people. It would also be useful to the public sector, because the data generated might be very helpful in the setting of research priorities and the allocation of funds for the applied engineering and diffusion stages of technology's lifecycle.

Current activities of Federal agencies are primarily oriented to the collection of data by etiological categories of impairments (and sometimes by disabilities). Less frequently do agencies collect data concerning limitations on functional abilities. The information that might be gathered from individualized plans (see ch. 3) is not seen as a source of raw material for the development of marketing-related data bases. Especially absent in data collection efforts are data on handicaps—i.e., disabilities turned into handicaps by an interaction of the disability and the physical and social environments. If data were available on the demographics (e.g., age, income, sex, other characteristics) of populations divided by types of functional limitations, the task of projecting the needed characteristics of technologies and the potential market for them would be made somewhat, perhaps considerably, easier. Such an outcome might be beneficial not only to the economic health of the private sector, but also to the public sector and the Nation as a whole.

Chapters 2, 3, and 11 discuss the issue of data based on functional limitations in more detail. One important point in regard to the collection of such data by the Bureau of the Census is that the design and testing of the surveys should be done with the substantial advice of disabled people, Government program administrators (especially of R&D activities), other data collection agencies and experts (e.g., the National Center for Health Statistics (NCHS)), and industry representatives. Alternatively, an agency with more experience in the disability field, such as NIHR, might coordinate the data collection and analysis efforts with the assistance of the Bureau of the Census and NCHS. The key point here is that one agency should have the responsibility for national data on disabilities in order to achieve uniformity of definitions and measurements, but that agency must draw on the pertinent technical resources of other agencies. Although it might be possible for a private organization to perform these functions, an advantage of using a Federal agency is the ability of the Government to access the medical and other records from which many of the data would come.

The Federal Government recently conducted a substantial planning effort for a very similar data collection activity. An interagency committee (including, NCHS, the Bureau of the Census, and NIHR) was established and pretested a survey instrument for the Census Disability Survey. That survey, using 100,000 disabled people and designed to collect information on functional abilities and disabilities, was to be a follow-on to the 1980 census. If the survey had been funded, and if it had been successful, it would have provided a substantial portion of the information needed by Government agencies, industry, and other groups. Lack of funds was cited as the reason for the project's not taking place.

The costs of option 1D would vary considerably, depending on how extensively the current survey techniques and activities of the Bureau of the Census would have to be modified or expanded. It might be possible to create a mechanism whereby the private sector, including industry, advocacy groups, and foundations, could contribute funds to the effort. Another dimension along which costs would vary is the extent to which new data are collected as opposed to old data analyzed to provide new answers. A recent study of national sources of data by the Bureau of Social Science Research (BSSR) concluded that the current sources in regard to disability data do not lend themselves to making national estimates. According to BSSR, the data from these sources exhibit numerous inconsistencies. However, because of the cost of designing and implementing new surveys, a second best alternative to gathering new data might be to establish an adequately funded effort to reevaluate existing data to get more accurate and more useful information. This alternative might be a fiscally easier first step.

A critical aspect of the success of this option would be the effectiveness of the dissemination of the generated data. Methods would have to be developed to allow all relevant parties to easily learn what would be available and how to gain access to it.

INVOLVEMENT OF DISABLED PEOPLE AND OTHER CONSUMERS

ISSUE 2

How can policies and programs be designed to encourage or assure the effective involvement of disabled people and other consumers in the development and delivery of technologies? In addition to providing information, consumers should themselves be part of advisory and policymaking bodies to the maximum extent feasible.

In theory, assuring maximum effectiveness, efficiency, and relevance in the development and application of technologies requires the extensive involvement of those who will use the technologies—the consumers. In practice, however, there is fairly little involvement.

There is no "correct" amount of consumer involvement, and there is no easy way to achieve *effective* involvement. OTA found the area of consumer involvement to be one filled with much irony. Consumer involvement is one of the most talked about aspects of the disability-related policy area—and everyone seems to believe in the concept—but few satisfactory schemes to improve the situation were suggested to OTA and few people or agencies appear to be taking aggressive steps to put the concept into practice.

OTA found a number of reasons for inadequate consumer involvement. One major reason is attitude. Although it is possible that, as a group, people working in the disability area are less prejudiced against disabled people than are other people, it appears that prejudice still plays a significant role in the willingness and desire of people in this area to interact with disabled people. Another major reason is simply a bureaucratic one. Program administrators or service delivery individuals naturally seek to simplify their functions; adding another source of review, oversight, or advice is not usually compatible with the bureaucratic outlook.

A third reason for lack of involvement is the outlook of disabled people and handicapped people themselves. Despite dramatic changes in their view of themselves and their abilities, many people still are reluctant to consult to, or get involved in the administration of, programs addressing disabilities. When people do not see themselves as having something to contribute, they are less likely to be asked to do so.

A fourth reason is the difficulty of identifying "consumers." Should a program seek any disabled person? A "representative" person? A representative from a consumer organization? From a coalition of organizations? How handicapped or disabled does the person have to be? One irony in this area is that the more articulate and mobile a disabled person is, the less *handicapped* (as defined in ch. 2) he or she likely is. Some people with disabilities may not be "handicapped," since they can perform life's functions substantially as well as a "nonhandicapped" person. Does this make them less representative? Not necessarily, but it makes the selection of consumers more difficult. Furthermore, consumers can include parents of disabled children, physicians and other providers, bus riders (both disabled and nondisabled), etc. Do parents always represent the needs and desires of their children and others' children?

Another, very critical, reason for the inadequacy of consumer involvement is a lack of knowledge about how to design the advisory mechanisms that consumers would fit into in order to ensure effective involvement. In equal opportunity programs, in urban renewal, in education, and in many other policy areas, the country has sought to use consumer (affected party) involvement. Many of these efforts have been less than successful. That does not mean that they accomplished nothing, merely that they did not come close to meeting expectations or their potential contribution to policy formulation or implementation.

The tactical goal of consumer involvement is *realism*. Consumers and the groups or organizations they interact with should gain a more realistic appreciation of the others' needs and capabilities. Designing a subway system that will handicap many disabled people is perhaps worse than designing a system with a plan for handling disabled people in a particular way, without the initial and continuing involvement of disabled people. Even so, the latter approach may not be the most effective or efficient way to make the system accessible and may also generate a priori resistance on the part of disabled people. Early, extensive involvement of potential disabled riders in planning for a new system might inject an element of realism: Subway designers and financers, may gain a more realistic idea of the needs, desires, and capabilities of disabled people and be made aware of alternatives to their plan; *and* disabled people may gain a more realistic idea of

Photo credit: Association of Handicapped Artists

Confined to a wheelchair by cerebral palsy, Neita May Kimmel of Catawissa, Pa., has appeared before high school, college, church, and club audiences to show and tell of her work and that of the Association of Handicapped Artists. She has written a book, "Reaching for the Stars," in collaboration with Dr. Raymond Treon the design and financial constraints operating on the subway builders, thus allowing them to suggest possible alternatives within the constraints.

OTA found that R&D of technologies often proceeds with little input from potential users. When involvement is sought, it may be perfunctory. The everyday, realistic needs of users very often do not find expression in the funding of R&D by the Federal Government. Nor are consumers represented very often on the groups that perform evaluations of technologies. (These shortcomings are addressed under the option area below on the research, development, and evaluation of technologies.

Consumer involvement is critical at each stage in the lifecycle of technologies. If Federal programs change their orientation from one of concern with simply the *needs* of consumers to concern with a mix of *needs, desires, and capabilities* (see ch. 2), the lack of consumer involvement will become even more critical. Besides R&D and evaluation activities, marketing, delivery, and financing programs need information that can best be provided by those directly affected.

The options provided below for the issue area of consumer involvement are organized by the degree of formality involved. This does not mean that they are necessarily mutually exclusive. More formal action may be desired in one area of policy (e.g., research project review, or consumer review of technologies for coverage under Medicare) and less formal actions in others (e.g., oversight hearings on compliance with individual education program (IEP) preparation and use).

OPTION 2A

> *Congress could mandate formal consumer involvement in any or all Federal programs or federally funded programs related to the development and use of disability-related technologies.*

As mentioned above and in other parts of this report, Congress has already mandated consumer ("handicapped persons") involvement through several Federal laws. The National Council on the Handicapped, for example, must have consumer representation, and the individualized educational program, individualized written rehabilitation program, and individual habilitation plan processes are designed to involve disabled people or their parents or other representatives in decisions about education or rehabilitation.

Under this option, Congress could expand the formal, statutorily based, requirements for the participation of disabled people in the policy development and implementation processes. Numerous agencies, including the Department of Health and Human Services (DHHS), the Department of Education, VA, the Department of Labor, and the Small Business Administration, could be required both to involve disabled people directly and to support consumer activities.

Direct involvement of consumers could be mandated in the process of R&D. (Option 3A also attempts to accomplish this.) Consumers would provide valuable advice to the process of setting research priorities, evaluating grant and contract proposals, and evaluating reports of progress on existing grants and contracts. The process of peer review would thus be expanded to include a more realistic appreciation of research needs and the usefulness of results.

Agencies that finance the use of technologies or that directly provide technologies to people with impairments and disabilities (e.g., VA) could set up panels, composed wholly or partially of consumers, to review technologies that might be included in reimbursement schedules or purchase lists. Alternatively, the Health Care Financing Administration (HCFA), NIHR, and VA could jointly fund a private nonprofit organization of consumers to review proposed technologies.

In general, this option could involve a program-by-program review to determine which programs could use the various mechanisms for establishing or expanding consumer involvement. As discussed above, *effective* consumer involvement is difficult to achieve. Thus, consideration should be given wherever possible to the use of flexible mechanisms—e.g., combinations of advisory panels, staff hiring, and contracts with consumer groups.

OPTION 2B

> *Congress could mandate an office of consumer involvement to monitor and provide assistance to other offices dealing with technologies, and Congress could encourage all*

relevant agencies to expand consumer involvement.

Instead of legislatively mandating consumer involvement in specific instances, Congress could clearly encourage various agencies to expand their consumer involvement activities. This option provides the advantage of flexibility—flexibility to change as conditions change over time and as data on the performance of involvement methods become available. Congress could encourage specific actions through oversight hearings, committee reports, and other means.

The obvious disadvantage of this option relative to the previous one is the difficulty of gaining voluntary compliance by the agencies. That disadvantage is part of the rationale behind the creation of an office of consumer involvement to coordinate, monitor, and provide technical assistance regarding the involvement of disabled people. The legislative record, including hearings, committee reports, and the law itself, would serve as mechanisms for signaling the intent of Congress to encourage involvement. Further, the office could be required to submit annually to Congress a report on all relevant executive branch activities.

Another reason for the creation of an office of consumer involvement coordination and technical assistance is the desirability of *effective* consumer involvement. Achieving effective participation will not be easy; thus, providing agencies with an office that possesses expertise and experience in techniques to encourage such participation could be very helpful. It would be a small office with a modest funding level.

The proposed office, perhaps with the assistance of an interagency advisory or coordinating committee, could monitor all consumer involvement activities, keep standardized records of these activities and any evaluations of their outcomes, maintain lists of consumer organizations and individuals who may be called upon, advise agencies on methods of increasing consumer activities, evaluate agency activities, and report on its own and other agencies' activities to Congress, the President, the National Council on the Handicapped, and any other designated groups.

The office could also be responsible for testing the feasibility of, and perhaps eventually implementing, a management information system based on data from individualized plans (as described in ch. 3) in order to evaluate and support involvement of consumers and consumer-generated information.

OPTION 2C

Congress could encourage agencies to increase consumer involvement activities.

If Congress wishes to signal a concern about the inadequate amount and quality of consumer involvement activities, it could do so through mechanisms less formal than legislation. These mechanisms include, as noted above, oversight hearings and records of hearings, and language in committee reports accompanying related legislation. Such informal, though official, encouragement has some potential to effect change. However, in view of tight agency budgets, bureaucratic inertia, and the difficulties inherent in attempts to achieve fully useful consumer participation, it is likely that this option possesses substantial disadvantages.

RESEARCH, DEVELOPMENT, AND EVALUATION OF TECHNOLOGIES

ISSUE 3

How can R&D activities be organized and funded to produce knowledge, techniques, or devices that serve the needs of disabled people and relevant providers in accordance with the magnitude of various problem areas and opportunities? How can evaluation of present and emerging technologies be organized to provide consumers, providers, and policymakers with adequate information?

R&D activities and related evaluations must be adequately funded, their potential contribution to the ultimate goals of technology application must be recognized, and their organization be such that it support the attainment of those goals. In the area of disability-related technology, however, as discussed in chapters 6, 7, and 10, these needs for R&D and evaluation activities fall short of being realized.

Excluding the general health research of NIH, the amount of Federal funds spent on R&D related to disabilities is approximately $66 million. (This figure includes education and vocational-related R&D, but not R&D in areas such as transportation or housing; even if these other areas were included, it is unlikely that the figure would be substantially increased.) In contrast, transfer payments alone to disabled people from Government programs total $36 billion. Thus, *R&D expenditures represent about one-fifth of 1 percent of the transfer payments. If the other public and private sector expenditures for services to disabled individuals were added to the transfer payments, the R&D budget would be an even smaller percentage.* These comparisons are not meant to suggest that there is any way to identify a "correct" amount to spend on disability- or handicap-related R&D. (Total Federal health R&D is about 2 percent of total national personal health care expenditures—a figure that, at a minimum, is 10 times greater than that for disability R&D.)

Similarly, the level of evaluation activities is extremely low. No figures for the total effort in evaluation of disability-related technologies are available. However, it is clear that relatively little formal clinical or life-use testing takes place (see ch. 7). The reality of competition for funds certainly affects the levels of both R&D and evaluation activities. For evaluation, though, a perhaps equal factor is the lack of recognition given to the potential contribution of evaluation to decisions about the appropriate application of technologies.

The organization and directions of R&D and evaluation also contribute to the inadequate number of useful technologies from these activities. The peer review systems in effect at the start of the OTA study were not well organized (see ch. 6), although that situation appears to be changing. *Inadequate attention is paid to what will happen to the results of R&D once development is completed. The constraints and demands of marketing, production, and consumer acceptance and preferences continue to play a relatively small part in the R&D process, though that situation also seems to be changing—slowly.*

Methods of evaluation and analysis remain underdeveloped. Recent work of NIHR and RSA seems to be moving in promising directions, but such work may not be a priority item for those agencies. Cost-benefit and cost-effectiveness techniques and modified forms of comprehensive technology assessment show potential in this area, but these methods are not being investigated thoroughly.

Complex, expensive technologies continue to recieve a large share of NIHR's and other agencies' R&D funding. Complex, expensive technologies are not inherently more or less appropriate to concentrate on than simpler, inexpensive ones. R&D and evaluation funding should be apportioned among different technologies according to their potential for appropriate applications to the needs of consumers; such funding should not be apportioned on the basis of investigator interest or how fascinating or futuristic a technology may appear. The R&D process should be organized according to the needs it is designed to satisfy. More attention could be given to the apportioning of R&D funds by the potential payoff of various efforts in various technological areas. Some areas need more basic research, others need development funds, and others have technologies that need diffusion assistance. In short, attention should be divided according to the state of maturity—"readiness"—of the technologies and the nature of the population in need. NIHR and other agencies already have the authority to take many of the needed actions; they do not have to wait for legislative change. Agencies could, for example, allocate increased funds for low- or middle-technology fairs and contests. (Such fairs or contests should not become ends in themselves, but should be followed by publicity and publications summarizing the ideas generated.) Also, agencies could devote resources and attention to development and testing of methods of evaluation.

OPTION 3A

Congress could mandate that consumers and production and marketing experts be represented on R&D panels and evaluation panels.

This option explicitly recognizes that considerable involvement of the people and organizations who will play a major role in the subsequent usefulness and diffusion of technologies should take place early in the processes of R&D and evaluation. The objective of this option is the improvement of systems for conceiving new technologies, adapting existing ones to new applications, allocating R&D funds, and evaluating the results of current or past R&D. Congress has already indicated its desire that consumers and other groups be represented on the National Council on the Handicapped. The council is involved in setting or recommending directions and policy for NIHR. This body, however, cannot play a role in each R&D allocation decision; nor can it serve as the only source of consumer, production, and marketing input to the entire R&D and evaluation process. Further, its influence is far less extensive in agencies other than NIHR.

Implementing this option would require extensive thought on the most effective ways of avoiding tokenism and conflict-of-interest situations for private industry. Effective consumer involvement has often been a goal of many public policy areas, yet that goal is difficult to achieve. Questions have been raised, for example, about the effectiveness of consumer representation on the Food and Drug Administration's medical device classification panels. However, the addition of consumer, production, and marketing experts to disability-related R&D peer review and other groups may be somewhat more effective. Many aspects of the R&D process for technologies that will be used by disabled people are amenable to experienced consumer input. Consumers might inject a degree of realism to the setting of R&D goals and priorities; evaluation criteria might be set to more closely resemble the list of factors that lead to a technology's successful application. A consumer does not have to be a mechanical engineer to know that wheelchairs must fit through doors.

Production and marketing experts could help the R&D process in several ways. For example, the simple presence of such people on panels could remind researchers and policymakers that the end result of R&D is supposed to be (in most cases) useful and cost-effective techniques and devices. Also, their experience and expertise would allow them to make suggestions concerning the evaluations that are necessary and the technological characteristics (reliability, cost to produce, ease of repairs, potential demand, flexibility) that should be sought. Such experts might help in the process of considering potential technologies, whether complex or simple, in relation to their eventual application and distribution.

Theoretically, no congressional actions are necessary for the adoption of this option. The executive branch agencies could implement it by themselves. If Congress finds that it is a desirable option, however, and agencies do not implement it on their own, Congress could amend relevant laws to mandate that R&D-related peer review and other advisory groups have such representation.

OPTION 3B

Congress could mandate demonstration projects for the awarding of "production stage" grants or contracts early in the R&D process.

The objective of this option is similar to that of the previous one. The ultimate goal of most R&D efforts is the development of technologies or techniques that will be effective *and* will be distributed—i.e., successfully reach their market. Small grants or contracts to nonprofit or profit-seeking organizations to analyze the potential market and to develop plans for the efficient production and diffusion of specific technologies *may* help. This option is oriented to only a demonstration effort because of the many questions that exist concerning the effectiveness of such a mechanism. Enough potential exists for the idea to be given consideration by Congress, however, and, if Congress believes it is warranted, for the idea's trial through pilot projects.

Congress could specify, either in renewal legislation or in appropriations language, its desire that NIHR (and perhaps NASA and VA) develop such a demonstration program.

One method of implementing the demonstration would be to select through a competitive process a firm that is interested in the marketing rights, for a specified time or area, for a particular technology. That firm would use the contract funds to examine the most efficient ways to produce the technology under development. It could suggest changes in the technology or the populations for which the technology is being designed. It could aid in any evaluations of the technology. Essentially, this option is designed to set up a strong positive incentive for organizations to produce and market technologies.

The grants or contracts should not be so large that organizations would seek them without a real desire to eventually market the technology. The funds should be set at an amount that covers part or most of the cost of the activities in conjunction with the R&D process, as listed above. The hope for this option is that it will reduce the risk and the cost of deciding to market the technology, thus allowing a more intensive look at the appropriate potential applications of that technology.

OPTION 3C

> *Congress could appropriate specific increased funds for evaluation of technologies.*

This option follows from the discussion of the relatively low level of funds and activities currently existing in the disability area. Although current economic realities naturally affect the viability of this option, it is important to remember that the current level of funding for evaluation is extremely low and that the number of technologies in need of clinical and other forms of evaluation is increasing constantly (see ch. 7). Especially pertinent is the probability of an acceleration of the number of technologies being developed. Many observers speak of the "explosion" in technologies for disabilities. Although the term "explosion" is a dramatic one, it is clear that advances in solid-state electronics, other communications developments, new alloys, and medical advances are producing numerous new technologies. Some of these may produce dramatic effects, others may turn out to be useless, but most will produce benefit under certain conditions—i.e., when applied appropriately in relation to their costs and risks. An increased amount of funds will be needed to adequately assess these new technologies as well as existing ones. The money, attention, and personnel will have to come from existing resources, which are already scarce in the disability-related R&D area, or from new funds specifically indicated for evaluation. Further, in the absence of increased funding—from whatever source—of evaluation, it is likely that program funds will not be spent in as efficient a manner as might be possible.

One drawback to this option is the immaturity of analytical techniques for comparing costs, risks, benefits, and social implications of disability-related technologies. The direct health-related benefits and risks can be estimated through relatively sophisticated techniques (using controls and statistical methods), but other effects are less amenable to current methods of evaluation. Thus, selection and implementation of this option may require that some initial attention and resources be devoted to the development of methods of analysis. Additionally, if this option is adopted, the very fact that increased funding, and therefore researcher attention, will be devoted to the area may mean that more work will be done on methods.

OPTION 3D

> *Congress could conduct oversight hearings with the Department of Education to determine why the dissemination of information on technologies remains inadequate.*

OTA finds that the amount, usefulness, and accessibility of information on the characteristics, availability, and performance of technologies are not meeting the needs of users or potential users. Interviews with researchers, administrators, and consumers and with disabled people and nondisabled people; a review of the literature; and the results of OTA's public outreach survey all reveal that dissemination of information is inadequate.

There are many partial explanations of the inadequate state of information flow that exists. One, for example, is that the National Rehabilitation Information Center (NARIC) is relatively new, and its ABLEDATA system is even newer. Also, these activities have not had significant amounts of funds appropriated. Thus, while ABLEDATA appears to be a potentially model system for disseminating information on assistive devices, the number of devices about which information has been entered into the ABLEDATA system and the amount of data on each such device are still quite limited because of the small size of the staff. Another reason is the generally low level of information that exists. It is difficult to disseminate what is not available or is of poor quality, low relevance, or nonstandardized. This is one reason that option 3C would assist in improving the performance of information dissemination activities, particularly for evaluation information.

Furthermore, experts in the field disagree on the best way to approach the collection and dissemination of data on disabilities and technologies. Some people believe that a large, centralized data system for the collection of masses of data is not the most effective or efficient method. However, others believe that such a single standardized system is necessary. The evidence available to OTA indicates that one system is not the answer, given the nature of disabilities and the disability field. There is a wide variety of parties who have a number of differing information needs. Disabled people themselves represent one of the largest groups of potential users of information. Yet the data needs of disabled people are as varied as the disabilities, desires, and capabilities they possess. Still, questions remain about the alternatives to a single system.

Before any specific legislative actions are taken, a number of questions could be addressed in oversight hearings. Such hearings could be designed to bring out more clearly the reasons for the current situation and the administrative reactions to that situation. Examples of questions that could be explored in oversight are the following: Why have agencies, especially in the Department of

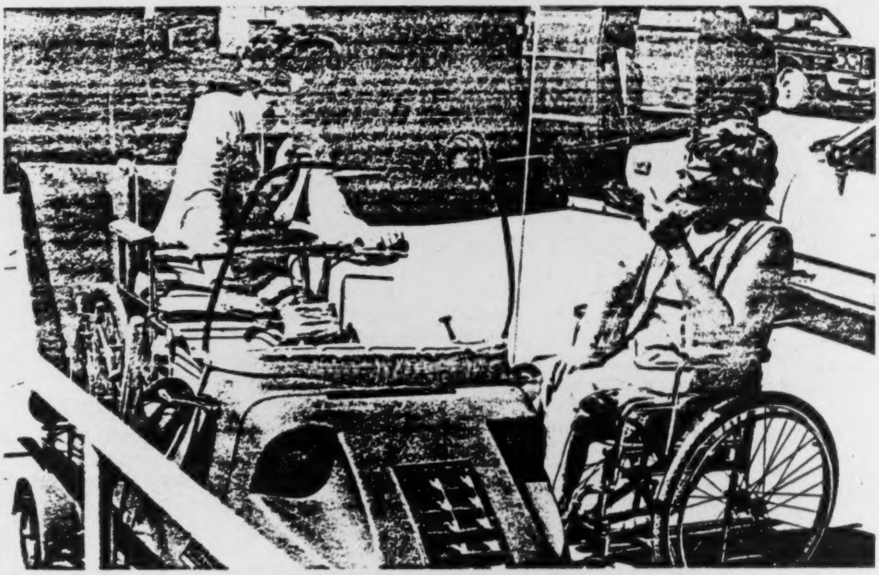

Photo credit: Barry Corbet. Courtesy of North American Reinsurance Corp.

Imogene Dickey of Buffalo, Wyo., uses a wheelchair for mobility. She and the chair ride on a Chair-E-Yacht or, for longer distances, a ramp-equipped van

Education, oriented their dissemination activities to professional research institutions and similar clients? What is being done to establish the criteria for the design of a system to make information available to disabled people directly? What effects might be expected from an increase in the funding levels for NARIC and, especially, ABLEDATA? Why has little effort gone into the standardization of evaluation and performance data on technologies? How will disabled persons not enrolled in public programs have access to information on technologies? Do agencies plan to expand their evaluation activities in regard to the performance of any existing systems for disseminating information, including NARIC (and specifically ABLEDATA) and any non-Federal systems?

Oversight questions could also address the factors cited above that make dissemination difficult and explore what the agencies are doing to minimize the difficulties, or to compound them.

Depending on the results of any oversight hearings, Congress may then decide to take substantive legislative action or to encourage specific actions by the agencies.

FINANCIAL BARRIERS TO THE USE OF TECHNOLOGY

ISSUE 4

How can financial barriers to the acquisition of technologies by disabled people be reduced, within reasonable constraints? Can the levels and distribution of available funding be made more appropriate in relation to the level of the problems addressed?

Imperfections in the structure of delivery systems need to be minimized. Inadequate and sometimes illogical criteria for reimbursement or payment for technologies should be reviewed and where appropriate changed.

Despite eligibility for the public and nonpublic programs that may pay for technologies to assist them to function more independently and productively, *a number of disabled people are denied funding for particular technologies that are clearly appropriate.* As discussed in chapter 9, a primary reason for the denial of funding—especially under Medicare and Medicaid, but also under other programs—is that the technologies in question are not strictly "medical" in nature and are therefore not considered "necessary." A connection needs to be made in these programs between paying for these technologies and the potential independence or productivity of disabled people. Another finding is that when device technologies *are* funded, services necessary to their proper use (e.g., fitting, training in correct usage, and maintenance) are often not included in the funding. Furthermore, OTA finds that decisions to fund certain technologies are sometimes based on the criterion of low initial, short-term cost. Use of such a criterion may fail to identify instances when a greater initial investment might result in decreased long-term costs and greater functional ability for the individuals involved.

While most indigent disabled persons are eventually able to receive *some* assistance towards meeting their needs, OTA finds that *acquisition of technologies in the period immediately following the onset of their impairment presents particular financial hardships.* Those individuals who must leave their employment because of their disability often lose the insurance coverage that would have funded the technologies. Eligibility for a Federal program may be established, but benefits are provided only after a number of months have elapsed. Earlier intervention through funded technology would often serve to reduce or ameliorate disabilities during the early stages and thus lessen the long-term disability.

OTA finds that disabled people with enough resources to prevent their participation in programs that pay for technologies also face serious financial barriers to technology acquisition. *There are few available methods for financing the capital outlays that are often necessary, and those few that exist are available only in selected parts of the country.* Additionally, there is a need to expand the use of innovative ways to eliminate financial barriers to the use of technologies. One such method that shows promise is pooling of devices by schools, voluntary health or disability organizations, hospitals, or similar organizations. This approach should be taken only with great care, however, since pooling of obsolete or simply "left over" technologies from other users could lead to inappropriate matches between the new user's needs and the available pooled technologies.

OPTION 4A

Congress could establish a loan guarantee program with low interest financing (on an income-related sliding scale) to assist disabled people in device purchases.

This option would reduce or eliminate financial barriers to acquiring devices for individuals who have the capability to generate the funds to pay for the devices but who do not have the recources for the initial capital outlay. Either the amount of money available for the loan or its interest rate, or both, would vary according to the financial need of the individual beneficiaries. The rationale for such a program is straightforward—the loans would assist in the purchases of devices which, in turn, would assist the individuals directly or indirectly to function independently, work, and pay back the loan.

Pursuit of this option would likely involve a minimum of Federal dollars. The program could be State-administered, as is the program of federally guaranteed student loans for higher education. Adding this new program to a similar one for administrative purposes would minimize the funds spent on administration. The interest subsidies could be provided either by the Federal Government directly or by the lending institutions with tax incentives to do so. The actual Federal funds necessary for coverage of defaulted loans could be kept at a minimum as long as the beneficiaries of the program are selected to fulfill criteria that would increase the likelihood of their ability to repay the loans.

A significant implication of this option is the public-private partnership likely to occur if it were implemented. Such a partnership might be an important advantage in an era of pressures to constrain expenditures of public dollars.

OPTION 4B

Congress could conduct oversight hearings on ways to change criteria for reimbursement under the Federal health insurance programs with respect to technologies for disabled people.

This option is developed from OTA's finding that disabled people eligible for coverage under one of the Federal health insurance programs are often denied payment for technologies that are not considered strictly medical in nature, although the technologies would improve the ability of the individuals involved to lead more independent, productive lives. The current patterns of reimbursement exist largely because of the history of these programs as assistance for acute medical problems rather than for the chronic problems faced by disabled people. The legislation for the programs does not expressly prohibit payment for "nonmedical" technologies such as communication, education, and rehabilitative aids. Instead, the denials usually occur at the State or regional level through regulation.

A significant effect of the current "system" is that in the short term, funds may be saved, while in the long term, a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses. In addition to the cost-related effects, there are psychological effects on the individuals involved—the current system provides incentives for the dependence of disabled people on public programs. Changes enacted should provide incentives for independence.

Hearings on methods to change reimbursement criteria to foster independence and productivity would focus attention on the need to consider the implications of policies in one area on other related areas. Such hearings, if pursued, could include testimony by consumers and providers of disability-related nonmedical technologies as well as by representatives of HCFA, the State Medicaid offices, and the contractors. Theoretically, the hearings should provide alternative criteria for expanded reimbursement and suggested regulatory changes to accomplish that objective which HCFA and the States could then adopt. Congress could then hold oversight hearings at a later date to determine the effects of any adopted changes. However, it is possible that legislative action may be required to assure expanded reimbursement. In that case, the actual law should include safeguards against abuse of the expanded opportunities for reimbursement. One method would be to detail the criteria for payment in the law directly.

Finally, OTA finds that reimbursement for an expanded variety of technologies should not be pursued without accompanying reimbursement for the services of those who select the technologies, those who fit them, and those who train the users in their proper use. A portion of the oversight hearings could address various criteria for assuring that these essential related services will be provided.

OPTION 4C

Congress could conduct oversight hearings on methods to improve health insurance coverage for persons leaving employment as a result of disability.

The objective of this option is to reduce the financial barriers to the acquisition of technologies during the period immediately following termination from employment due to disability. The option stems from OTA's finding that the systems for assistance are least able to assist disabled people during that time, although some form of early assistance may prevent or reduce assistance at a later time. Most people who leave employment lose health and medical insurance coverage formerly provided by their employers. Even if they are eligible for public or private disability income maintenance payments, they often do not have the funds to purchase private individual coverage. Since health and medical insurance programs are a primary source of funding for technologies for disabled people, Congress could investigate ways to close these gaps and examine the resultant benefits and costs to society of any administrative or legislative action implemented.

One method that might be covered in oversight hearings is the provision of Medicare coverage during the 29-month period that individuals must wait for Federal disability insurance. This method should be used only for those people who do not have private insurance or other financial resources readily available to them. Criteria for providing Medicare coverage (e.g., a likelihood of having the severity of the disability reduced as a result of early medical intervention), or methods for measuring fulfillment of the criteria could be topics for testimony. Another method that might be covered is the provision of incentives to employers to provide health and medical insurance coverage to their terminated employees for 12 to 29 months following termination for disability-related reasons.

It is likely that legislative action will be necessary to implement any of the methods presented. Such action could range from changes in the Social Security Act to minor changes in tax deductions. The amount of Federal dollars will vary according to the source of the coverage (Federal or private), the amount of coverage extended, and the number of new beneficiaries. A potential drawback to this option is that it is not designed to improve coverage for those disabled from birth or those disabled later in life who are not working at the time of disability onset. Furthermore, unless changes in the criteria for reimbursement under the Federal health insurance programs are pursued as discussed in the previous option, there is likely to be an inefficient expenditure of dollars under any program arising from these hearings as long as appropriate technologies are not covered.

PERSONNEL ISSUES

ISSUE 5

How can Federal policies assure an adequate number of well-trained personnel at all stages of the development and use of technologies? Systems for R&D as well as delivery of services should provide incentives for the cost-effective use of these personnel.

Although the actual number of professionals (disabled and nondisabled) working to develop and apply technologies to disabled people has increased dramatically over the last 40 years, there remains a shortage in a number of key areas. First, there are too few rehabilitation researchers and rehabilitation engineers. Although difficult to quantify, this shortage can be described by the primary reasons behind it. One, as discussed in chapters 6 and 10, is the relatively low level of funds spent on disability-related research in relation to the amount spent on general health-related research. Another reason, as discussed in chapter 9, is a lack of reimbursement for the skills of these professionals, particularly rehabilitation engineers. Together these reasons result in an unfavorable job market that may discourage prospective students from entering those fields. Second, there are too few allied health professionals, including physical therapists, occupational therapists, orthotic and prosthetic technologists, speech therapists, vocational educators, and rehabilitation counselors. As in the case of rehabilitation engineers, the size of the shortage is difficult to quantify, primarily because demand figures for these professionals usually include the needs of nondisabled clients as well as disabled persons. It is clear, though, that legislation such as the Education for All Handicapped Children Act, as amended, has served to increase the demand for allied health professionals. Furthermore, there is a shortage in these areas of professionals who are disabled themselves.

Finally, there is a shortage of rehabilitation physician specialists, although the specialty has been in existence since 1948. Under the current reimbursement system, this shortage is often a key one, because it is often the physician who must prescribe a technology for it to be funded. OTA explored the reasons behind this shortage and found them to include a perception of the specialty as one with low status, a relative lack of control over the client's treatment due to the wide range of other professionals whose opinions must be considered, a lack of professional orientation towards the treatment of stable or deteriorating conditions, and a lack of training in the undergraduate medical education on the management of chronic disability.

Another key finding with respect to personnel is that *those providers who are permitted by the structure of the delivery and funding systems to select or prescribe technologies for disabled users may not be the most appropriate ones to do so.* Traditionally, physicians have prescribed most of the device technologies, partly because disabled people often receive their first services through the medical system and partly because the major third-party payers will pay only for items that carry a physician's prescription. For certain technologies, physicians are the most appropriate providers to make the best selection for their clients. However, for other technologies, particularly those that are not medical in nature, other providers are equally or better qualified to make the best selection. Yet if these other providers, including rehabilitation engineers, occupational therapists, and special education teachers, as well as users themselves, cannot obtain funding, their skills may not be fully utilized, and the overall costs to society may be greater. Changes in physician curricula as well as in reimbursement policies might alleviate this problem.

OPTION 5A

> *Congress could appropriate funds for the training of increased numbers of disability-related personnel, including rehabilitation engineers, rehabilitation medicine physician specialists, and allied health professionals.*

The objective of this option is to alleviate the shortage of providers in the development and use of technology. The option is weighted toward the application end of the technology lifecycle, since it is likely that researchers trained in related fields could apply their basic skills to the disability field if funds were available for new projects. Schools eligible to receive the funds under this option would include schools of engineering with specific programs for rehabilitation engineering, medical schools that sponsor residency programs in rehabilitation medicine, and schools for allied health professionals. As under the existing programs for training assistance (including public health, nursing, and physician traineeships), the funds could be awarded directly to recognized programs but applied to educate specific individuals. This mechanism allows nationally determined priorities to affect the selection of both the educational programs and the individuals in them. Funds appropriated for these programs might come from funds curently appropriated for physician training in specialties for which there is likely to be an excess according to the recent report of the Graduate Medical Education National Advisory Committee (102).

A corollary objective of this option is to encourage disabled individuals to become rehabilitation professionals, particularly rehabilitation engineers. As noted throughout this report, the appropriate application of technologies to disabled people requires input from consumers at every phase of the technology lifecycle. Because rehabilitation engineering is a blend of technology development and application, it is a key field in which to focus Federal efforts to encourage the training of disabled professionals. Mechanisms to encourage an increase in the number of disabled professionals trained include requiring or creating incentives for programs that receive Federal assistance to implement affirmative action programs.

This option will not be effective unless mechanisms for improving criteria for reimbursement for nonmedical technologies are developed, as discussed under options 4B and 5C. Currently, a lack of funding for nonmedical personnel who assist disabled people to function independently has made the job market undesirable for prospective students. Training more professionals for these positions would probably be an inefficient use of scarce resources.

Finally, an alternative to training more rehabilitation medicine specialists is training physicians in other specialties to become "managers" of the rehabilitation and habilitation of their chronically disabled clients. This alternative recognizes that physicians are likely to influence delivery and payment systems for at least the short-term future. Funding courses in medical schools or residency programs might assist other physicians to better help their disabled clients.

An additional need in this area is for the training of existing disability-related and general health professionals in the specialized skills necessary for the appropriate use of technologies.

OPTION 5B

Congress could encourage volunteer participation in assisting disabled people by modifying tax incentives related to volunteer expenses and charitable contributions.

As with the previous option, the objective of this option is to alleviate the personnel shortage in various parts of the technology lifecycle. This option suggests the use of volunteers to perform some of the functions normally provided by professionals, to enhance the services provided by professionals and to assist in implementing existing legislation that has, to date, not been appropriated enough funds for full implementation (e.g., the Education for All Handicapped Children Act). Although "volunteer participation" suggests that no compensation is provided, the incentive of reduced taxes is known as a relatively inexpensive method of providing compensation. This option assumes that the provision of such "compensation" will increase the supply of volunteers. Although tax provisions currently exist both for deduction of charitable contributions and volunteer expenses, strengthening these provisions might increase volunteer participation. For example, the current deduction of 9 cents per mile of volunteer travel by automobile might be increased (for business travel, the current deduction is 20 cents).

Specific examples of possible volunteer assistance are: serving as information resources and referral persons (a function often performed by several types of allied health professionals); assisting in planning and conducting education and training programs on the application of existing and emerging technologies (a function performed by allied health professionals when performed at all); assisting in the evaluation of new products and services (a function often neglected); conducting self-help groups for peer counseling (an activity best performed by disabled volunteers); and donating money or goods. Possible strengthened tax incentives are: tax credits (instead of deductions) for some portion of charitable contributions; deductions for more than 100 percent of expenses incurred in providing services that otherwise would not be provided because of budget cuts; deductions for expenses incurred by families who provide services to disabled members of the family who would otherwise be served under a publicly funded program; and deductions for activities which might affect the environment of disabled and handicapped people in a positive way (e.g., an attitudes awareness campaign by a television station).

Because the expenses incurred under this option, if adopted by Congress, would be primarily in the form of lost tax revenues rather than direct outlays, few Federal dollars would be expended if volunteer activity were not increased. A potential drawback to this "solution" to provider shortages, however, is the lack of quality control over volunteer activities.

OPTION 5C

Congress could mandate the funding of demonstration projects to test reimbursement for technologies under Federal health insurance programs by the types of skills provided rather than by the types of providers.

This option is in response to OTA's finding that those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so. In some instances, therefore, a client may not receive the proper assistance, or the skills of several providers (those able to prescribe and those unable to) may be employed at more expense and loss of efficiency than necessary or desirable. Another problem is that services necessary for the proper use of prescribed technologies are often not reimbursed under the Federal health insurance programs (see option 4B) if they are not provided by a physician and are therefore not provided. So far, there has been no proven method established to solve these problems, although numerous suggestions have been made. A program of demonstration projects mandated by Congress is proposed under this option in recognition of the untested status of this potentially helpful solution.

Because reimbursement experiments are common under the Medicaid and Medicare programs, it would be logical that HCFA administer this demonstration program. Congress could provide the Secretary of Health and Human Services with the authority to issue waivers from current Medicare and Medicaid rules to demonstration project participants when it next amends titles XVIII and XIX of the Social Security Act.

In order to meet the objectives of providing more appropriate, cost-effective services and assuring that services are of an acceptable quality, Congress might want to limit the types of services eligible for the program in its authorization of the project. Alternatively, each pilot project might limit the types of services reimbursed by service to an area in which the project's sponsors had already demonstrated quality and effectiveness. The funds appropriated for the demonstrations should be sufficient to assure quality; the limits should be placed on the number of projects.

Dr. GIBBONS. There are five overlapping issues:

How can we improve the production, marketing, and distribution of technologies for disabled people?

How can we more effectively involve disabled persons in analysis and decisionmaking concerning the development and use of technologies?

How can we make the process of developing and evaluating technologies more responsive to the needs of disabled people?

How can we reduce the financial barriers to the use of these technologies?

How can Federal policies help assure a well-trained and adequate supply of personnel in disability-related disciplines and services?

By devoting attention to a combination of the above issues, and by developing an approach that involves the private sector, disabled consumers, and government, we can do much to take advantage of technology's growing potential to enhance the lives of disabled people.

Gentlemen, this concludes my summary testimony. Mr. Behney and I would be pleased to respond to any questions.

[The prepared statement of Dr. Gibbons follows:]

STATEMENT OF

JOHN H. GIBBONS, DIRECTOR
OFFICE OF TECHNOLOGY ASSESSMENT
CONGRESS OF THE UNITED STATES

BEFORE THE
SUBCOMMITTEE ON RESEARCH, SCIENCE AND TECHNOLOGY
COMMITTEE ON SCIENCE AND TECHNOLOGY
UNITED STATES HOUSE OF REPRESENTATIVES
AND THE
COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ON
TECHNOLOGY AND HANDICAPPED PEOPLE

SEPTEMBER 29, 1982

Mr. Chairmen and Members of the Committees:

I am pleased to appear before you to summarize the OTA study, Technology and Handicapped People. Accompanying me is Mr. Clyde J. Behney, the project director for the study and OTA's Health Program Manager.

The study was requested by the Senate Committee on Labor and Human Resources. We were asked to examine how technologies for disabilities are developed, evaluated, and put into use, and then to identify any problems or missed opportunities related to that process. The study also identified policy options for Congressional consideration. With your permission I would like to submit a copy of the Report's summary for the record.

The Federal Government is deeply involved in programs that affect the use of technologies for disabilities. Programs cover research and development, marketing, financing of technologies, civil rights and their enforcement, employment, transportation, health care, income maintenance, independent living, and many other aspects of life. Concerns have been raised about consistency of objectives, conflicting incentives, and lack of appropriate distribution of technologies.

Clearly, technology exerts a powerful influence over the lives of everyone, making life easier, more fulfilling, but sometimes more painful and frustrating. This statement is especially true for people with disabilities.

Many people have modest impairments, and others are significantly disabled in their ability to perform one or more important life functions. These limitations either are present from birth or occur from injury, disease, or aging. Whether an impairment becomes a disability depends on many things, including technology. Whether a disability becomes a handicap depends on the interaction of the disabled person with the physical and social environments surrounding that person, and many other factors. And, again, technology is one of those factors.

Some technology, especially medical technology such as knee implants or eyeglasses, can eliminate or reduce impairments and keep them from becoming disabilities. Other technologies are used extensively to prevent disabilities from becoming handicaps by, for example, making transportation systems and accommodations accessible. Disability technology may be complex, e.g., a voice-activated power wheelchair, or simple, e.g., special utensil attachments. Disability technology is used to facilitate "mainstreaming" in education, to prepare disabled people for employment, to adapt job sites to the capabilities of disabled persons, and to create manageable home environments.

The OTA Report's major conclusion is that despite the existence of numerous, important technical problems related to developing technologies, the more serious issues are economic and social ones. For example,

* reimbursement and financing are sometimes not adequate or efficient. For example, reimbursement levels for durable medical equipment under Medicare and Medicaid were found to be so low that many needed devices cannot even be purchased at those levels. Also, reimbursement may encourage purchase of inexpensive versions of devices such as wheelchairs even though increased replacement and repair expenses may outweigh the savings.

* the goals of Federal policies are sometimes conflicting and ill-defined. For example, some programs (such as vocational rehabilitation) are oriented to employment and independent living; others (such as Medicare and Social Security programs) are governed by a "medical" orientation; other are a confusing mixture (e.g., the Veterans Administration). The two different outlooks result in confusing differences in eligibility, services, and use of technologies. An (artificial speech) communications device, e.g., might be paid for by an employment oriented program but not by Medicare, on the grounds that it is not a "reasonable and necessary" part of medical care.

- many of the Federal programs that provide or pay for technologies have strong civil rights aspects (e.g., education, accessible housing and transportation). Often, there is uncertainty regarding the philosophical and political basis of these programs. Are they efforts to compensate for past inequity, or are they efforts to distribute resources on the basis of an equal, present, right to a satisfying quality of life? These basic uncertainties lead to uncertainty about how to implement the programs and about the specific ends to be sought through technology.

WHAT DO WE MEAN BY IMPAIRMENTS, DISABILITIES, AND HANDICAPS?

The term impairment refers to the physiological, anatomical or mental loss resulting from accident, disease, or congenital condition. Generally, an impairment results in a disability when a basic human function such as eating, hearing, seeing, speaking, or walking is limited. It results in a handicap when a disabled person comes into contact with a handicapping social or physical environment, such as an absence of accessible transportation to get to work.

Technology for disabled people plays the role of improving the compatibility between individuals and their environments. By making a distinction between "disability" and "handicap," OTA recognizes the necessity of studying both individuals and the environments in which they function.

The key to appropriate development and use of technologies lies in finding a compromise between: 1) the needs, desires, and capabilities of users and other relevant parties; and 2) the costs, risks, and benefits of technologies. Such compromise may be simple when, for example, deciding to prescribe or wear eyeglasses. However, some compromises may be far more complicated; for example, whether to consider a myoelectric limb.* In such cases, an explicit framework for analyzing technical alternatives becomes very important.

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* A myoelectric arm, for example, is an artificial, electro-mechanical limb controlled by the individual through use of existing nerve endings at the place of attachment, usually the upper arm or shoulder.

TECHNOLOGY AND DISABILITY: FINDINGS

The U.S. Government spends about $66 million a year on R&D related to technologies for disabilities. However, the U.S. government also spends more than 500 times that amount - about $36 billion - each year just to support the income of disabled people. Thus, its R&D expenditures in this area represent only 0.2 percent of its transfer payments. When other costs related to disability are included, such as health care, the percentage becomes even smaller.

Despite problems, disability-related R&D is characterized by innovation. Given sufficient funding and an effective organization of efforts, the predicted "explosion" in relevant technologies could become reality. Advances in solid-state electronics, other communications/information developments, new alloys, micro-computer-aided movement (e.g., of artificial limbs), and biomedical knowledge, including neurochemistry, are already producing dramatic improvements as well as new possibilities. The future may see an acceleration of technological contributions. Some advances, such as writing aids for physically disabled children, may have great value; others may turn out to be useless. Most important, though, is planning for and identifying the appropriate ways to evaluate, distribute, and use the breakthroughs.

Evaluation of technologies should be an integral part of the R&D and marketing process. For disability-related technologies, however, OTA found inadequate attention is being given to evaluation. This finding is especially true for criteria such as repairability, convenience, cost, consumer satisfaction, funding or reimbursement status and potential, and cost-effectiveness. Evaluation becomes particularly crucial in view of the possibility of a significant increase in the number of technological advances, such as in the area of communications devices or mobility aids. Unfortunately, this area of technology has not had a tradition of evaluation and is presently subject to very low funding for evaluation.

There are relatively few examples of successful Federal efforts to bring a product developed under a Federal R&D program to private manufacturers for mass marketing and distribution. The Veterans Administration, the National Aeronautics and Space Administration, and the National Institute of Handicapped Research are lead agencies for the successes that have occurred. The reasons for the lack of success include several that arise from the specific characteristics of the disability-related market: the disability population is ill-defined; the economic status of users is often far below the average; disability-related technologies often do not appear viable from a strictly "market" perspective, resulting in a lack of private interest in their production; product liability is often perceived by manufacturers to be a problem; and, especially, the systems for third party reimbursement of devices sometimes discourages the marketing of certain types of technologies.* In addition, many of the factors that hinder the successful commercial application of government-funded research in any technological area also apply in the disability area. For example, government support is often given for research and development of technologies that are complex and expensive, making them less competitive in the marketplace. Also, the public patent status of government-sponsored technologies can be a disincentive to their later commercial development.

The use of technologies by disabled people depends primarily, but certainly not entirely, on their eligibility for public and nonpublic programs that provide the devices and related services. This is partly because many disabled people have lower than average earnings and partly because the programs are the primary source of information on available technologies. Through their affiliation with these programs and services, users either receive devices and services directly, have them financed, or learn about them. The programs consist mainly of: 1) Income maintenance, 2) health and medical care, 3) social services, 4) educational services, and 5) vocational rehabilitation and independent living.

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* At the same time, it is important to point out that third party reimbursement, e.g., under Medicare, is also one of the largest sources of funds for disability technologies.

OTA found that the current system of disability-related research, development, evaluation, diffusion, and use suffers from a number of significant weaknesses. The system could be capable of providing a great deal more service, even with existing levels of funds. For example, inadequate attention is being paid to the concept of appropriate technology; that is, finding a compromise fit between the device and the user. Analytical methods for determining and attaining the proper match of technology and user need to be developed and applied over the lifetime of the disabled person. In addition, information on available technologies is often fragmented, so that disabled persons, rehabilitation workers, insurance companies, and other individuals and groups may have difficulty locating needed data. Strengthened information dissemination is urgently needed.

WHAT ARE THE POLICY ISSUES AND OPTIONS?

Providing disabled individuals with the advantages offered by technology requires the resolution of several policy issues. Federal policies on financing and R&D of technologies would be greatly improved if they encouraged criteria for devices such as rate of obsolescence, ease of maintenance, ease of actual procurement by the user, and users' preferences. A disabled person might then have a better basis, for example, for selecting a manual wheelchair over a power wheelchair.

The OTA Report presents a series of issue areas and related options, which will be considered at the Capitol Conference on Technology and Handicapped People. I would be pleased to submit a copy of the issues and options chapter from the Report for the Record and mention to you only the issue areas that the options address. There are five overlapping issues:

* How can we improve the production, marketing, and distribution of technologies for disabled people?
* How can we increase, and make more effective, the involvement of disabled persons in analysis and decision making concerning the development and use of technologies?
* How can we make the process of developing and evaluating technologies more responsive to the needs of disabled people?
* How can we reduce the financial barriers to the use of these technologies?
* How can Federal policies help assure a well-trained and adequate supply of personnel in disability-related disciplines and services?

By devoting attention to a combination of the above issues, and by developing an approach that involves the private sector, disabled consumers, and government, we can do much to take advantage of technology's growing potential to enhance the lives of disabled people.

Thank you for inviting me, Mr. Chairmen. I will be happy to address any questions.

Senator **Hatch**. Thank you, Dr. Gibbons. We are going to refrain from asking questions so we can allow witnesses to testify. I want to congratulate you and Mr. Behney for the excellent work you have done. We may want to put more money and effort into it to expand this record.

You have covered the physical handicapped area quite well. The areas we perhaps have not covered are the emotional and mental retardation-type handicaps that are equally very difficult to deal with without continual investment in high technology and technological development and advancement to help these folks.

I just want to personally congratulate you on the work you have done.

Dr. **Gibbons**. Thank you, Mr. Chairman.

Mr. **Walgren**. Mr. Chairman, I, too, would like to add my compliments and encouragement for OTA's involvement in this area. If I could break the rule that I think we should set for ourselves, which is that we are not going to pursue, certainly in great detail, questions and the like, there is one area I would like to give you a chance to comment on. It strikes me that one of the rapid potentials for change in the lives of disabled people is with the explosion of computer technology and data transmission. There is certainly an increasing potential for people to be constructively employed in that area. My question is, Is there a focus in our governmental system for providing for employment of disabled people? I am just so disappointed with the lack of specific employment opportunities for handicapped people in our society that I wonder, is there any direction we can give on this level?

Dr. **Gibbons**. Let me make a very brief response, and I will ask Mr. Behney if he would like to add his response to your question.

It is quite clear that the workplace is becoming more and more dependent on the exercise of the human mind rather than the human back. The availability of technology to assist a person with physical handicaps to carry out a task has never been greater. It represents an explosion of new capability to provide mechanisms to enable a bright person who is physically handicapped to be able to be an immensely important contributor in the workplace.

I share your concern that the opportunity is now. I am not that sanguine about whether this fact is reflected in Federal training programs.

Mr. **Behney**. The brief answer to your question is no. We do not know of any specific focus in the Federal Government on the use of computer and information technology, on related training or services or pieces of equipment, or where substantial funds are being put into it.

I think it is fair to say this is more of a private sector activity. There are many private sector organizations collecting information on this, developing software, disseminating information and so forth. In this area of communications and computers, as in many areas, there is no Federal or State-level focus where the various things can be brought together. There are programs that are concerned about it because it is an important and growing area, but it is so explosive and so diffused that we are probably missing a great deal of it at the Federal level, and at most of the State levels. So the answer is no. More of it is in the private sector, and it is a gap that is serious.

Senator HATCH. I think the Congressman's question is a good question, and something we should explore further. It may be the answer to helping a lot of handicapped people who are very capable of doing constructive and good work in our society who have not the opportunity today because of the lack of applicable technological use and utilization.

We appreciate the work you have done. We may be back at your door again asking you to expand on this report. It is an excellent report as far as it goes, and we just want to congratulate you for it.

Thank you for being here.

Our next witnesses will be part of a panel. We are happy to have the three of you with us today. We admire the work that you do.

If I could on a point of privilege just express the point that I consider it a great privilege to be able to introduce a resident of my own State, Dr. Alan M. Hofmeister. He is currently the dean of the school of graduate studies and associate vice president of research at Utah State University.

Dr. Hofmeister is internationally acclaimed for his work in special education. He received the highest award given from the Governor and Legislature of Guam for development of exemplary teacher training and service delivery programs. He also earned the outstanding teacher and special education award and received the Joseph P. Kennedy fellowship. A renowned researcher, Dean Hofmeister has published numerous articles and books dealing with the technology of the handicapped. He has served as the principal investigator for a myriad of grants and contracts dealing with microcomputer and video disks.

He served as a consultant to CBS, the Department of Education, the State Department, other universities, and of course other publishing companies. He was elected as the national president of the Association for Special Education Technology, and coordinated the interdisciplinary doctoral program for technology and special education at Utah State University. Before obtaining his present assignment he served as the department head of special education at Utah State University. So it is with a great deal of pride I introduce you to our two committees today, Dr. Hofmeister, and we are grateful that you have taken time to travel back here and be with us today. I am certainly grateful to you other two excellent authorities in the field, and we are grateful to have all of you here today.

[The biographical sketch of Dr. Hofmeister follows:]

VITA ABSTRACT

Alan M. Hofmeister, Dean, School of Graduate Studies, Associate Vice President for Research, and Professor of Special Education, Utah State University

1. Earned degrees:
   (a) Teacher's College Certificate, Queensland Teacher's College, 1958, (Major: Elementary Education).
   (b) Diploma of Physical Education, University of Queensland, 1961, Bachelor of Education, Queensland University, 1965, (Majors: Psychology, Educational Research).
   (c) Master of Science (with honors), University of Oregon, 1967 (Majors: Corrective Physical Education, Special Education).
   (d) Doctor of Philosophy (with honors), University of Oregon, 1969 (Major: Special Education).

2. Specific teaching experience with handicapped children and youth:
   (a) Consultant in motor training to residential schools for the retarded, blind, and deaf, 2 years.
   (b) Supervisor, Adult Training and Rehabilitation Program, Pearl Buck Center for the Retarded, Eugene, Oregon, 1968-69.
   (c) Clinical experience; Schonell Center, Queensland, Australia; DeBusk Center, Eugene, Oregon, 2 years.

3. Special areas of expertise are instructional technology, microcomputer applications in special education, parent training, and educational research.

4. Significant related publications over the 1977-81 period:

Hofmeister, A. M. The parent is a teacher. Paper presented at the Utah State University 56th Faculty Honor Lecture, Logan, Utah, November, 1977. Abstracted in Resources in Education, 1979. (ERIC Document Reproduction Service No. ED 161 541).

Hofmeister, A. M., & Gallery, M. A method for assessing the treatment validity of tests in special education. The Exceptional Child, 1978, Vol. 25, No. 2, 105-113.

Hofmeister, A. M. Testing and treatment validity. Journal of Learning Disabilities, 1979, Vol. 12, No. 3, 73-75.

Hofmeister, A. M., Atkinson, C., & Henderson, H. When a Child Misbehaves. Chicago: Developmental Learning Materials, 1977. Also printed in paperback and titled: What Do I Do Now? Niles, IL: Argus Communications, 1978.

Hofmeister, A. M. What directions should research take in developing educational programs for the severely handicapped. In R. Heinich & S. C. Ashcroft (Eds.) Educating All Handicapped Children. Englewood Cliffs, NJ: Educational Technology Publications, 1979.

Hofmeister, A. M., & Thorkildsen, R. Videodisc technology and the preparation of special education teachers. Teacher Education and Special Education, 1981, Vol. 4, No. 3, 34-39.

Hofmeister, A. M. Microcomputers in education: Fact or fad? Keynote speaker and paper presented at the Association of Media Producers Conference, Washington, D. C., September, 1981.

Hofmeister, A. M. Handwriting Resource Book: Manuscript/Cursive. Niles, IL: Developmental Learning Materials, 1981.

Hofmeister, A. M. The Videodisc and Educational Research. Paper presented at the Annual Meeting of the American Educational Research Association, New York City, March, 1982.

Hofmeister, A. M. Microcomputers in perspective. Exceptional Children. 1982, Vol. 49, No. 2. (in press).

STATEMENTS OF ALAN M. HOFMEISTER, DEAN, SCHOOL OF GRADUATE STUDIES, UTAH STATE UNIVERSITY, LOGAN, UTAH; JEAN ELDER, COMMISSIONER OF ADMINISTRATION OF DEVELOPMENTAL DISABILITIES, DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND MARK OZER, PROFESSOR OF CHILD HEALTH AND DEVELOPMENT, GEORGE WASHINGTON UNIVERSITY, WASHINGTON, D.C.

Dr. HOFMEISTER. Before I start I would like to follow up on Mr. Walgren's observation regarding computers. There is a large initiative being undertaken by Control Data Corp. that addresses your concern, and I am sure that corporation would really appreciate any Federal involvement in the planning. Control Data has set aside a large amount of money to help integrate the handicapped in the developing processes in computer science.

Senator HATCH. I have been to Control Data, at their home offices, and I have had an overview of their programs. I want to pay personal tribute to them. The work they are doing is not necessarily high-profit-motivated work, but it is work that really is needed in this society. As you know the chairman of the board of Control Data is a person who has set some tremendous standards for corporate America to do more and more good in society, rather than just worry about profits.

Now they have to worry about profits, too, we all understand that, but I just want to personally congratulate the people at Control Data for some of the innovative things they are doing in this area, and your highlighting that today I think is helpful to the committees.

Dr. HOFMEISTER. Thank you, Senator.

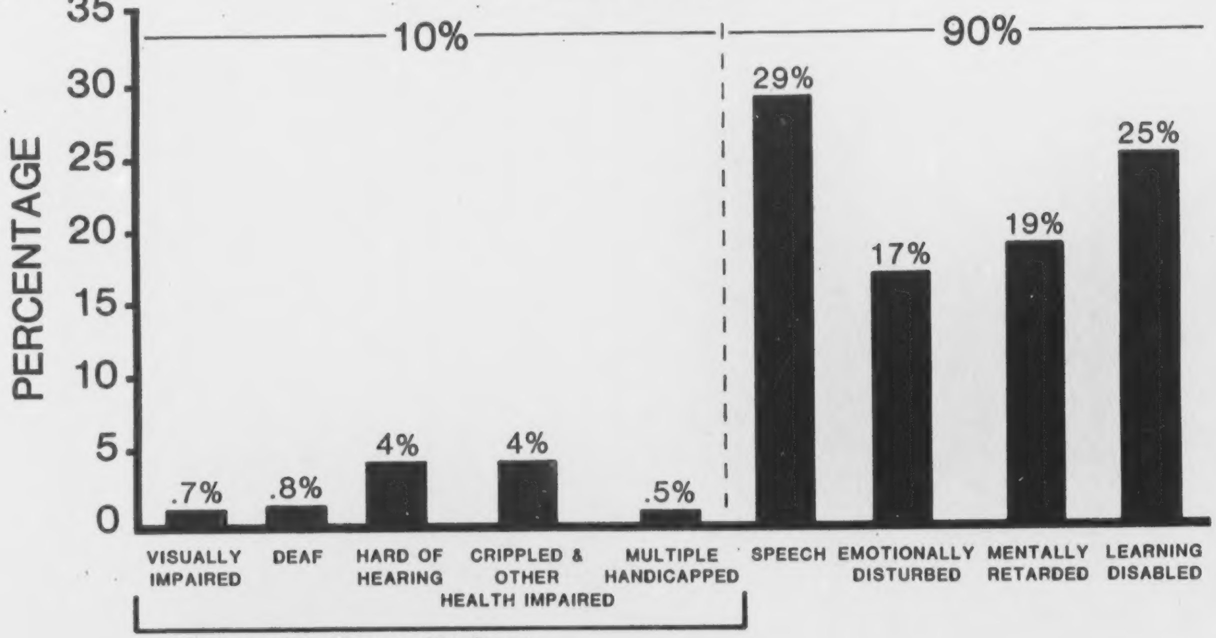
My thanks to Senator Hatch, Chairman Walgren, and Congressman Brown for the opportunity.

These observations are being made in my role as a past president of the Association for Special Education Technology and an active researcher in the application of microcomputer technology and videodisc technology to the needs of the handicapped.

My purpose in making observations regarding the report, "Technology and Handicapped People," is not to question the accuracy of the content—rather I hope to draw attention to what I consider to be a serious omission. The report addresses the application of technology to the needs of individuals with physical or sensory handicaps.

[The information follows:]

FIGURE 1: PREVALENCE RATE OF SCHOOL-AGE HANDICAPPED (12.035%)*



Handicapped Emphasis in OTA Report:
Technology & Handicapped People May 1982

*Report To Congress: Unanswered Questions on Educating Handicapped Children in Local Public Schools HRD-81-43, February 5, 1981.

Dr. **Hofmeister**. As shown in figure 1, the majority of handicapped served in the schools do not have the major physical and sensory handicaps stressed in the report. The majority have speech impairments, intellectual handicaps, and emotional handicaps. We use the terms "mentally retarded," "learning disabled," "speech impaired," and "emotionally disturbed" to cover this large segment of the handicapped population served by the schools. The report does not focus on this population nor the technologies of most concern to these handicapped individuals or the professionals charged with the provision of services to these individuals. I would strongly urge that consideration be given to the following issues.

The major type of service we provide the school age handicapped is educational. Instructional technologies must be a major concern. We must immediately concern ourselves with the problems and the potential of technological developments in such areas as:

TELEVISION TECHNOLOGY

Television technology is going through major changes worldwide. England and France are experimenting with national information systems using an adaption of cable television. Several large companies are experimenting with "teletex and videotese" demonstrations in the United States. The captioning of television for the deaf, although not a recent development, has yet to be extensively implemented.

COMPUTER TECHNOLOGY

Of interest under computer developments are such issues as:

First, computer-assisted instruction—its potential and problems;

Second, computer-managed instruction, for example, the application of computers to monitor the implementation of programs for the handicapped;

Third, the vocational potential of computers, for example, opportunities for high-status employment for less mobile individuals;

Fourth, computer literacy, for example, the problem of an increase in environmental complexity for mentally and emotionally handicapped persons.

TELECOMMUNICATION AND SATELLITE TECHNOLOGIES

Included in this area would be: One, the potential for high-quality services to be delivered to rural and remote areas; and two, the enhanced ability to communicate with parents and homebound or hospitalized individuals.

THE URGENCY OF THE PROBLEM

One of the problems we face with many of these new technologies is the fact that they will be implemented and they will impact the handicapped individual whether or not we are prepared to effectively guide this implementation.

To exemplify this concern, I would like to make reference to the computerization of society. This computerization is creating both problems and opportunities for the handicapped. For those professionals charged with maintaining the intellectually handicapped in the mainstream, the rapidly increasing need for computer literacy poses a problem for those individuals already having considerable difficulty adapting to the present level of technological complexity in our society.

This computer revolution also offers opportunities. The maximization of these opportunities will require prompt and thoughtful action. Computer-assisted instruction is a rapidly developing technology that offers promise for a level of individualization in instruction never before possible. Private industry is in the process of investing millions in the development of software for education. Many of these companies would be very interested in data on procedures that would help the software under development serve the needs of the learning disabled and the mildly mentally retarded.

Without the research and development to guide the developers of this new software, we may see a situation in which these millions of dollars being invested in the development of the software will be used to restrict educational advancement rather than to enhance the learning opportunities of the handicapped. This restriction will occur if the software adds to the learning problems of a handicapped individual. For example, most of the mildly handicapped in the schools have reading problems. Much of the software being developed is being designed to replace large portions of the teacher's oral communication with the textual communication of the computer screen. Will such "individualization" be helpful to the poor reader?

I would like to strongly support the report's emphasis on personal assistance devices and services. We are in need of information on the modifications that are necessary to insure that the handicapped receive the personal assistance services necessary. A modification of television through captioning, the use of computer touch screen and voice synthesizer to simplify computer interaction for nonreaders or nonspeakers, are examples of the adaptations to meet individual needs of the handicapped.

When we look broadly at the issue and include the school population handicapped and the adaptive educational technologies I think we may have to rethink some of the conclusions of the report. I am particularly concerned about the emphasis on the joint public-private corporation marketing and the observation that the Federal Government has not set a good record in this area. A serious omission, as far as exemplary practice in this area, is the Office of Special Education. It has had in place a market linkage program for 5 years. Its project was recently commended by the President's Task Force on Private Sector Initiative. During the last 5 years some 118 R&D products have been moved into the private sector for distribution. When the project started only 2 percent of the targeted private companies were preparing and adapting materials for the handicapped. At this point in time there are now 15 percent of the same private companies preparing adaptive materials for the handicapped. I think when we look at the success of the Office of Special Education in this area, and we look at the success of NASA, we may want to rethink the notion of another added administrative process and possibly look at making the individual agencies responsible and accountable for the market linkage themselves.

In closing I would like to make the observation that when we deal with the issue of technology and handicapped people, we should not forget that handicapped children are people.

Thank you.

[The prepared statement of Dr. Hofmeister follows:]

OBSERVATIONS ON REPORT:

"TECHNOLOGY AND HANDICAPPED PEOPLE"

by

Alan M. Hofmeister
Dean, School of Graduate Studies
Associate Vice President for Research
Utah State University

Testimony before the Senate Committee on Labor and Human Resources and the House Subcommittee on Science, Research and Technology, of the Committee on Science and Technology, September 29, 1982, Washington, D. C.

OBSERVATIONS ON REPORT:
"TECHNOLOGY AND HANDICAPPED PEOPLE"

Introduction

These observations are being made in my role as a past president of the Association for Special Education Technology and an active researcher in the application of microcomputer technology and videodisc technology to the needs of the handicapped.

Purpose

My purpose in making observations regarding the report, "Technology and Handicapped People," is not to question the accuracy of the content--rather I hope to draw attention to what I consider to be a serious omission. The report addresses the application of technology to the needs of individuals with physical or sensory handicaps. As shown in Figure 1,* the majority of handicapped served in the schools do not have the major physical and sensory handicaps stressed in the report. The majority have speech impairments, intellectual handicaps and emotional handicaps. We use the terms "mentally retarded," "learning disabled," "speech impaired," and "emotionally disturbed" to cover this large segment of the handicapped population served by the schools. The report does not focus on this population nor the technologies of most concern to these handicapped individuals or the professionals charged with the provision of services to these individuals. I would strongly urge that consideration be given to the following issues.

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*In the school age population, 12.035% are handicapped. Figure 1 shows the distribution of this 12.035% across the different categories of handicapping conditions.

Instructional Technologies.

The major type of service we provide the school age handicapped is educational. Instructional technologies must be a major concern. We must immediately concern ourselves with the problems and the potential of technological developments in such areas as:

Television Technology

Television technology is going through major changes worldwide. England and France are experimenting with national information systems using an adaption of cable television. Several large companies are experimenting with "teletex" demonstrations in the United States. The captioning of television for the deaf, although not a recent development, has yet to be extensively implemented.

Computer Technology

Of interest under computer developments are such issues as:

(1) Computer assisted instruction--its potential and problems;

(2) Computer managed instruction, e.g., the application of computers to monitor the implementation of programs for the handicapped;

(3) The vocational potential of computers, e.g., opportunities for high status employment for less mobile individuals;

(4) Computer literacy, e.g., the problem of an increase in environmental complexity for mentally and emotionally handicapped persons.

Telecommunication and Satellite Technologies

Included in this area would be (1) the potential for high quality services to be delivered to rural and remote areas, and (2) the enhanced ability to communicate with parents and homebound or hospitalized individuals.

The Urgency of The Problem

One of the problems we face with many of these new technologies is the fact that they will be implemented and they will impact the handicapped individual whether or not we are prepared to effectively guide this implementation.

To exemplify this concern, I would like to make reference to the computerization of society. This computerization is creating both problems and opportunities for the handicapped. For those professionals charged with maintaining the intellectually handicapped in the mainstream, the rapidly increasing need for computer literacy poses a problem for those individuals already having considerable difficulty adapting to the present level of technological complexity in our society.

This computer revolution also offers opportunities. The maximization of these opportunities will require prompt and thoughtful action. Computer assisted instruction is a rapidly developing technology that offers promise for a level of individualization in instruction never before possible. Private industry is in the process of investing millions in the development of software for education. Many of these companies would be very interested in data on procedures that would help the software under development serve the needs of the learning disabled and the mildly mentally retarded.

Without the research and development to guide the developers of this new software, we may see a situation in which these millions of dollars being invested in the development of the software will be used to restrict educational advancement rather than to enhance the learning opportunities of the handicapped. This restriction will occur if the software adds to the learning problems of a handicapped individual. For example, most of the mildly handicapped in the schools have reading problems. Much of the software being developed is being designed to replace large portions of the teacher's oral communication with the textual communication of the computer screen. Will such "individualization" be helpful to the poor reader?

Personal Assistance Devices and Services

To reinforce a point made in the report, I would like to stress that we are in need of information on the modifications that are necessary to ensure that the handicapped receive the personal assistance services necessary. A modification of television through captioning and the use of computer touch screens and voice synthesizers to simplify computer interactions for nonreaders are examples of the adaption of technology to meet the individual needs of the handicapped.

Expansion of Conclusions

When the findings of the report are expanded to these technologies and handicapped populations previously mentioned, some modification may be necessary in the findings of the report. For example, Option 1C (page 167) states, "Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and public sectors." This recommendation was based on earlier observations that ". . . the Federal Government does not have consistent, formal mechanisms in place to link research investment to the production and distribution needs of the marketplace" (p. 93). An observation is also made that NASA is an exception.

When the adaptive educational technologies are considered, credit must be given to the Office of Special Education (OSE). This office has had a market linkage project in place for several years. The project has facilitated the flow of a large number of OSE research products into the marketplace. The success that OSE and NASA have had suggests another approach--rather than develop a single large public-private corporation, make each R&D program responsible for the market linkage of its own R&D products.

Additional Documentation

To better document the issues, I have attached a review of technology from the perspective of those concerned with the school-age handicapped. While this review has some content in common with the OTA review under discussion, there is considerable variability in issues and approaches to technology.

Attachment
"Technology in Special Education," Reproduced
from The Fourth Review of Special Education,
L. Mann & D. A. Sabatino (Eds.), NY: Grune-Stratton,
1980.

Reproduced from: The Fourth Review of Special Education,
L. Mann & D. A. Sabatino (Eds.), NY:
Grune-Stratton, 1980.

TECHNOLOGY IN SPECIAL EDUCATION

A. Edward Blackhurst
University of Kentucky, Lexington

Alan M. Hofmeister
Utah State University, Logan

To many special educators, "technology" is equated with equipment and hardware such as audio-visual equipment, teaching machines, and computers. As the Commission on Instructional Technology (1970) pointed out in its report to the President and Congress, such a conceptualization is inadequate. While it is true that things such as television, films, projectors, and computers are considered components, technology is much broader than the use of items of hardware and software. As the Commission reported:

> Instructional technology is a systematic way of designing, carrying out, and evaluating the total process of learning and teaching in terms of specific objectives, based on research in human learning and communication, and employing a combination of human and nonhuman resources to bring about more effective instruction. (p. 19)

At approximately the same time that the Commission released its findings, Haring reviewed the application of instructional technology to special education curriculum design and concluded (Haring, 1970, p. 25):

> In the natural setting, educational technology is being applied in two ways: (1) through automated and non-automated media for display and measurement as part of the task of instruction, and (2) as a set of procedures which systematizes instruction.

Both the Commission on Instructional Technology and Haring were reflecting distinctions developed earlier by Banathy (1968), Dale (1967), Gagne (1968), Heinich (1968), and Silverman (1968).

Both authors are Past-Presidents of the Association for Special Education Technology.

In 1977, after an extensive study, the American Association for Educational Communications and Technology (AECT) adopted and published a comprehensive definition of educational technology. Space limitations preclude the reproduction of this 16-part definition; however, the introductory sentence states (AECT, 1977, p. 1):

> Educational technology is a complex, integrated process involving people, procedures, ideas, devices, and organizations for analyzing problems and devising, implementing, evaluating, and managing solutions to those problems involved in all aspects of human learning.

The AECT report goes to some length to differentiate between educational technology and instructional technology. However, it is common practice to use these terms interchangeably. Consequently, the terms will be used synonymously in this review.

Technology has been applied to many major problems in special education, with highly significant results. A summary of some of these major technological developments is presented in Table 1.

Regardless of whether or not technological applications have involved the use of machines, a common element has been the emphasis on systematic and integrated approaches to education. Nevertheless, considerable variations can be noted in the application of many of these systematic approaches. The particular field of research in human learning that a researcher chooses to stress is usually a major source of such variation. Haring (1970), for example, reported a strong preference for learning principles based on the experimental analysis of behavior (Sidman, 1960). In contrast, Scandura (1966) stated that some of the principles of learning theory were only of secondary importance in "real-life learning," and the entering competencies a child has may be more important than such principles as reinforcement.

Such differences in emphasis are still evident in special education today and may be associated with differing special education populations. Persons working with profoundly retarded children, where responsiveness to any environmental stimuli may be low, often stress principles of reinforcement. Those working with mildly handicapped persons, where curriculum content is more complex and pupil responsiveness to environmental stimuli is higher, may stress principles such as concept analysis (Becker, Engelmann, & Thomas, 1975). However, while areas of inquiry and approaches to instruction may vary, the common element in technological orientations is that the problems of learning and education are approached in a systematic fashion, regardless of whether media hardware and equipment are involved in the implementation.

In the following review of the application of technology to special education, it will be seen that two approaches, one stressing media applications and one stressing systems technology, are in evidence. The differences between the approaches are growing less distinct, as illustrated by the fact that persons working with media are tending to stress systems procedures to guide their product development processes (Thiagarajan, Semmel, & Semmel, 1974).

MEDIA TECHNOLOGY

Educational media are those nonhuman resources "born of the communications revolution which can be used for instructional purposes alongside the teacher, textbook, and blackboard" (AECT, 1977, p. 171). These generally represent devices (hardware) with accompanying materials (software) that are used to transmit messages (content). Some devices, however, are used primarily to facilitate communication or physcial functioning and do not require special software for their utilization, as will be illustrated later.

Because of space limitations and the relatively large potential body of information that could be covered in this section, the authors have elected to limit discussion to either relatively recent developments in the media field or to those devices that have specific applications to the handicapped. Several references will be made to secondary sources that provide composite reviews in several different areas, e.g., Lance's (1973) review of media technology and its implications for the handicapped. This document, the most complete review of media technology up to its date of publication, should be reviewed by anyone interested in this particular topic.

Computer technology

Computers are used with the handicapped for the same purposes they are used with the nonhandicapped, namely, computer-assisted instruction (CAI), computer-managed instruction (CMI), and information storage and management. Cartwright and Hall (1974) discussed many of these uses in a previous review. CAI has been shown to be effective with various handicapped populations (Fletcher & Beard, 1973; Goldenburg, 1977) and with their teachers (Cartwright, 1977). The increasing record-keeping and program-monitoring requirements of the Education for All Handicapped Children Act of 1975 (PL 94-142) have also given rise to the increased use of computers for general record-keeping purposes, such as the storing and updating of Individualized Education Programs

TABLE 1

SOME MAJOR MILESTONES IN TECHNOLOGY THAT HAVE AFFECTED SPECIAL EDUCATION

1808	The precursor of braille is developed as a series of raised dots for sending military messages at night.
1834	The braille code, using six dots, is published by Louis Braille.
1874	The audiophone bone conduction amplifier is invented.
1892	The Braille typewriter is developed.
[illegible]	The first electrical amplifying device for the hearing impaired is invented.
1913	Printed letters are translated to musical tones for blind readers using the Optophone prototype.
1914	The Tadoma method is developed for teaching deaf-blind children; the simplex hearing tube, which uses a funnel to catch sound, is invented.
1916	The Intelligence Quotient is introduced with the publication of the Stanford-Binet Scale of Intelligence.
1920	A human emotional response is conditioned by Watson in an experimental setting.
1926	Pressey develops a teaching machine that uses programmed instruction; a phonograph audiometer is developed to identify hearing impairments.
1928	Radios are distributed to blind citizens by the American Foundation for the Blind; seeing eye dogs are also introduced to the United States.
1930	A standard report form is developed for eye examinations.
1934	The printing visagraph is developed to enlarge printed pages and put them into raised form; the Gault Teletactor amplifies speech vibrations so that the deaf can receive them tactually; Talking Books for the blind are produced on long-playing records.
1935	The Waldman Air Conduction Audiometer is developed to detect hearing impairments.
1938	Pitch is translated into a visual image by the Coyne Voice Pitch Indicator.
1947	The Perkins Brailler is developed; printing of large-type books is initiated by The American Printing House for the Blind.
1949	Speech is transformed to visual patterns by the cathode ray translator.
1952	Blind students use the Stenomask to dictate lecture notes while listening.
1953	The megascope is invented to project and magnify printed material.
1954	B. F. Skinner publishes "The Science of Learning and the Art of Teaching."
1960	Lumsdaine & Glaser publish *Teaching Machines and Programmed Learning.*
[illegible]	Mager publishes "Preparing Objectives for Programmed Instruction."
[illegible]	Mobility in the blind is facilitated through the invention of the Kay binaural sensor; studies are performed using token economies.
[illegible]	The laser cane is developed for use by the blind.
1967	The National Society for the Study of Education 66th Yearbook is devoted to programed instruction.
[illegible]	A device is invented for compressing speech to more than 320 words per minute without distortion.
1971	The Optacon enables the blind to convert ink print to tactile impressions of letters.
1972	A braille writer of pocket size is developed; Kay Spectacles, which enable the blind to determine the precise location of obstacles, are developed as mobility aids.
1974	A braille calculator is developed; reading material can be magnified 25 times and displayed on a TV screen using the Visualtek Miniviewer; the electronic blackboard is developed to transmit writing over telephone lines for display on TV screens.
1975	A talking calculator is developed to provide audio output; speech synthesizers help persons with impaired speech to make spoken sentences; spectograms of speech can be frozen on a TV monitor using the speech spectograph display; Cybercom permits the severely handicapped to communicate via electric typewriter and message board operated by speech or a pneumatic switch; speed of recorded speech can be regulated using the Variable Speed Control Disc; individual educational programs are mandated for the handicapped in PL 94-142.
1976	The Kurzweil Reader translates printed material into synthesized speech for visually impaired persons; the partially seeing can enlarge ordinary printed material using the Optiscope illuminated enlarger; auditory stimulation can be provided to some deaf persons using cochlear implants; brain waves can be recorded during normal activity by an electroencephalograph vest.
1977	The development of artificial limbs is facilitated by the use of computer technology; a reduction of muscle spasms for some cerebral palsied and epileptic persons can be accomplished through the implanting of electrodes in the brain.
[illegible]	Paperless braille is invented to store printed materials on magnetic recording tape.

[illegible] Much of the material in this table was abstracted from the work of Nazzaro (1977).

(IEPs) (Lehrer & Daiker, 1978; Marshall & Johnson, 1978). It should be noted that use of the computer to manage special educational records creates special problems, particularly in regard to the issue of privacy of records. Grayson (1978) noted that because the computer can store and analyze information on a scale unthinkable by manual processing, the privacy of the individual is now threatened on an unprecedented scale.

Computers have, for many years, assisted in the diagnosis and testing of special populations through the remote scoring of tests and through direct on-line interactions at terminals (MacLeod & Overhew, 1977; Suppes, Fletcher, Aonatti, Lorton, & Searle, 1973).

The use of computers as aids in the diagnosis and remediation of speech problems has been evaluated with some evidence of success. For example in diagnosis and remediation efforts, the computer can analyze a client's speech and then provide a visual display of it. This has been found to assist the hearing impaired person to assess the quality of his or her speech (Boothroyd, Archambault, Adams, & Storm, 1978; Nickerson, Kalikaw, & Stevens, 1976).

The increase in the application of computers to special education has been closely linked to the development of microprocessor technology. The introduction of microprocessors has significantly decreased the costs and increased the capacity, reliability, and portability of computers and has extended their usefulness to the handicapped (Bodner, Hoelen, & Zogley, 1978; Foulds & Gaddis, 1975; Nelson & Cassalter, 1977). For example, small, personal computers developed for the home computer market have been applied to the instructional and communicative needs of the physically handicapped (Scully, 1978). Additional examples of such computer applications will be provided in later sections.

Telecommunication systems

The potential use of telecommunication systems for delivering educational services to exceptional children and those who work with them is great. However, this potential remains largely untapped: only a few projects have been conducted to explore the feasibility of their applications.

Graf (1974, p. 588) defined telecommunications as "all types of systems in which electric or electromagnetic signals are used to transmit information between or among points." The logic behind the electronic transfer of information was summarized by Wolff (1976 p. A 6–2):

1. Information is the raw material of instruction and learning.
2. The user should dictate the form, time, and place of needed information.

3. It is cheaper to move information to the user than to move the user to the information.
4. It is cheaper to move information electronically than any other way.
5. Most information can be stored, updated, and retrieved electronically.
6. All electronically stored information can be electronically distributed to large numbers of remote users.
7. Electronically stored and/or transmitted information can be given to the user in any electronically-related form such as cathode ray tube image, full audio-visual, computer printout, or facsimile.

Although assumptions 3 and 4 are probably not valid unless appropriate hardware is in place and certain economies of scale are met, the above propositions are well taken—particularly in light of the ever-increasing demands on individuals' time and current concerns over energy consumption necessitated by personal travel. With the advent of the video disc, video graphics, and fiber optic technologies that will be described in greater detail in the next section, they will probably have even greater validity in the future.

Blackhurst (1978) has described the various telecommunication systems that are currently available. He has also illustrated some ways that these might be used for educational purposes. These ways will be summarized in the remainder of this section.

The most readily available telecommunication system is, of course, the nation's telephone system. This can be used for transmitting lectures, conducting interviews, audio teleconferencing, transmitting data, and many other applications. Telephone systems have been very useful in providing instruction to homebound students (Carr, 1964). The telephone was first used for this purpose in 1940 (Hill, 1956). In a recent review, Parker (1977) concluded that classroom instruction conducted via telephone is at least as effective as face-to-face instruction.

In the area of special education, Hershey (1977) found that inservice training related to the education of the gifted conducted via telephone produced significantly higher performance than instruction that was provided in face-to-face or contrast group instruction. Tawney (1977a) demonstrated that telephones could also be used to link various interface and instructional devices located in the homes of severely handicapped infants to a central computer control station. CAI programs such as the PLATO system have also been transmitted over telephone lines (Ballard & Eastwood, 1974).

Computer conferencing (Infomedia Corporation, 1978) is a relatively new system that can be used via telephone lines. This system has been available since 1977, and enables anyone who has a computer terminal connected to a time-shared computer network to participate.

Users store messages in the computer for all persons who are participants. At any convenient time, by entering a code number, a user can query the system to determine whether there are any messages. If so, a response can be entered into the system to be retrieved at the initiator's convenience. This "electronic mail system" will have significant implications for remote conferencing and information exchange.

Open-circuit audio and video broadcast systems are most closely associated with either commercial or educational (public) radio and television. For the most part, these are single-channel systems that are expensive to operate and require special licensing. Obviously, if programing is to proceed over commercial channels it must have broad audience appeal. Educational programing for children, however, is frequently transmitted during school hours by educational television stations. These stations also broadcast inservice and credit courses for adults; however, these courses are becoming more infrequent and/or are broadcast at times that are inconvenient because educational stations are becoming more and more involved with the broadcasting of cultural programing and programing for children. Perhaps the greatest potential of mass media for serving the handicapped will be its role in educating the general public in matters related to the handicapped, such as was demonstrated by the nation-wide broadcast of the program, *Including Me*, in 1978 (Capital Cities Communications, 1978). This program provided an overview of different exceptionalities and showed how persons with different disabilities could be integrated into everyday activities. The considerable potential for mass media to affect the attitudes of children toward the handicapped has not been overlooked. Considerable emphasis has been placed upon incorporation of content related to the handicapped in children's programs such as *Mister Roger's Neighborhood* (Sharapan, 1973), *Sesame Street*, and *Zoom*. As Donaldson and Martinson's (1977) research also demonstrated, video and audio programing can also effectively influence the attitudes of adults toward the handicapped.

Community antenna television (CATV), which is now often referred to as cable TV, enables the provision of many television channels (normally 26 channels in most major market systems) to the ultimate user—whether it be the individual, school, or community center. The technology also permits, in many cases, interaction by the subscriber; that is, users may transmit "upstream" back to the studio (Baldwin, Greenberg, Block, Eulenberg, & Muth, 1978). This facilitates interactive audio, video, and computer utilization.

Instructional systems such as Time-Shared Interactive Computer Controlled Instructional Television (TICCIT) can be adapted for use with

cable technology, as was demonstrated in the New York project that provided instruction to homebound physically handicapped students (Tawney, 1977b). When used with other distribution systems, such as communication satellites, CATV holds great promise for the delivery of educational services (Parker & Riccomini, 1975).

Instructional Television Fixed Service (ITFS) is a special band of television channels reserved for the exclusive use of educational institutions. It was first established by the Federal Communications Commission in 1963 to respond to the needs of instructional television for multichannel transmission capability at costs considerably lower than conventional VHF or UHF television. ITFS operates at frequencies higher than those used by open broadcast stations. For this reason, special antennas and converters must be installed on each building which is to receive ITFS signals. This equipment converts the transmission to signals that can then be received by ordinary television receivers. Once established, ITFS is economical to use for regional applications: it permits flexibility, repetition, and interaction; and it reserves a place in the telecommunications spectrum for the exclusive use of the licensed operator (Blackhurst, 1978). Green and Lazarus (1977) have demonstrated how ITFS can be used to assist regular class teachers with mainstreaming problems.

Communication satellite systems can receive and transmit the signals of any electronic medium (Polcyn, 1973). They have the advantage that they are insensitive to distance, can reach areas that may be blocked by terrain such as mountains, and are useful in remote and sparsely populated areas that may be outside the range of other radio and television stations. A major barrier to the expanded use of satellites is the high cost of earth terminals and the limited availability of satellites and satellite time.

Two National Aeronautics and Space Administration (NASA) operated, high-powered experimental satellites have been used in a variety of educational experiments (Bystrom, 1974; Federation of Rocky Mountain States, 1975; Morgan, Singh, Rothenberg, & Robinson, 1975; NASA, 1974; Pal, 1976; Schwartz, 1976). The largest of these was in Appalachia, where inservice education, including courses related to the gifted and early childhood education of the handicapped, were broadcast to persons in an eight-state area (Bramble & Ausness, 1976). The great potential of communication satellites for educational purposes has received further elaboration by participants in a conference sponsored by the National Institute of Education (1977).

The Council for Exceptional Children (1978) also demonstrated the use of satellites to relay portions of the First World Congress on Special Education from Scotland to the United States. In another application, a portable satellite earth terminal was used to demonstrate how satellites could be used to facilitate live, audio-visual teleconferencing among special education teachers who were separated by approximately 2500 miles (Blackhurst, Williams, Churchill, Allen, & Siegel, 1980).

Future applications of telecommunications will most likely utilize hybrid systems that combine several technologies such as telephone, radio, ITFS, CATV, and/or satellites. Nilles, Carlson, Gray, and Hanneman (1976) concluded that telecommunications is a viable alternative to moving people. Their studies supported this conclusion on the basis of energy saving, attitude of participants, convenience, and student performance. However, they also concluded that the general public does not fully comprehend either the potential or the operation of such telecommunication developments.

Interface devices

In 1960, the implications of teaching machines for educating the handicapped were described by Stolurow (1960). Shortly thereafter, Glaser and his colleagues introduced the concept of the student–subject matter interface to the educational community (Glaser, Ramage, & Lipson, 1964). According to these individuals, an interface is any device that is used by students to facilitate their interaction with subject matter. More recently, such devices have also been referred to as man–machine communication systems (Kafafian, 1970) or communication end-instruments (Skinner, 1977).

Some of the implications of the interface concept for special education were illustrated by Blackhurst (1965), who speculated about various types of electromechanical devices that could be constructed to aid exceptional persons in their interaction with subject matter and with other individuals. It is interesting to note that many of the devices that were described in his article for potential future development are now a reality. In fact, technological advances have led to the development of interfaces that have gone beyond those that were being proposed approximately 15 years ago. Several of these will be highlighted in this section.

A major thrust of computer-related applications has been communication facilitation. Other technical aids also exist to support communication. Such aids range from the use of regular typewriters with mildly learning disabled pupils (Cothran & Mason, 1978) to complex and expensive closed-circuit television systems to magnify print for the visually handicapped (Genesky, Peterson, Clewett, & Yoshimura, 1978; Inde, 1978). Two of the best sources describing communication aids are the *Nonvocal Communication Resource Book* (Vanderheiden, 1978) and *Sensory Aids For The Blind And Visually Impaired* (American Foundation for the Blind, 1978).

The present-day communication boards with associated microprocessor technology (McDonald & Schultz, 1973; McNaughton, 1976; Von Bruns-Connolly & Shane, 1978) had origins in the diode–transistor systems of the mid-1960's. These early systems allowed the handicapped person, through a single paddle switch, to cause a light to scan behind an alpha-numeric display. When the desired character was reached, it could be held or typed on a teletypewriter (Roy & Charbonneau, 1974).

Nelson and Cassalter (1977) reported on the use of a microcomputer linked to two pupils with communication boards, a teacher, and a voice synthesizer. The communication boards utilized Bliss symbols, representing speech sounds. The synthesizer stored the name of each symbol in a memory as it was selected. On command, the whole sentence or phrase could be spoken by the synthesizer. Such systems are particularly relevant for persons with severe speech impairments.

A major benefit of such electronic communication aids lies in their ability to facilitate language development and language interaction. In some cases, dramatic improvements in language have resulted through their use, particularly in severely and multiply handicapped pupils whose potential had been grossly underestimated (Elder & Bergman, 1978; Kucherawy & Kucherawy, 1978). Along these lines Shane, Reynolds, and Geary (1977) have voiced a cautionary note with regard to the recent emphasis on nonvocal communication approaches for the severely handicapped, e.g., Bliss symbols. They recommend that an individual's verbal capability should first be explored carefully to determine potential for speech. They also note that it is possible to be severely handicapped, to appear nonvocal, and yet still have the potential to communicate verbally.

Microprocessor-based aids for the visually handicapped have been widely heralded (Sinclair & Sanderson, 1978). A hand-held, battery-operated calculator that speaks the name of each key as it is pressed is comparatively inexpensive and widely available (Brugler, 1978). The Opticon, which allows the blind person to read ordinary print through a conversion of the visual images to a tactile image and braille computer printing terminals, has received considerable acceptance (Joquiss, 1978; Ryan & Bedi, 1978). Since computers can now print in braille, information storage for the blind may be greatly facilitated. Compact and less expensive data cassettes can now serve to store information for them, as opposed to the space-consuming braille volumes of the past.

One of the most interesting interface devices, which has significant implications for the blind, is the Kurzweil reading machine. This computer-based device converts ordinary print materials, such as books, magazines, and typewritten correspondence, directly into spoken English at the rate of 150 words per minute. The user can also direct the machine to repeat or skip passages, spell out difficult words letter by letter, mark passages for future reference, and express the capitalization and punctuation in a sentence (Kurzweil, 1978).

A prototype braille information processor has also been developed for use by the visually impaired (Telesensory Systems, Inc., 1978). This electronic, "paperless" braille system is portable and enables the user to read braille on a 20-cell electronic tactile display rather than on paper. Thus, information for the blind may be stored on cassettes rather than on bulky braille paper. The user can also enter information into the cassette using a keyboard. A microcomputer then enables the user seeking information to automatically retrieve it from the cassette. Since the device is also an audio recorder, both braille and verbal messages can be stored. An optional visual display enables seeing persons to monitor and enter information into the system.

Galton (1977) reported on several other devices to aid the visually impaired. A cane has been developed that contains three laser beams that send out beams of light which result in auditory and tactile feedbacks if there are obstacles directly in front of the walker, a drop-off, or low-hanging obstacles in the person's path. Two other systems in prototype form also hold considerable promise for the blind. One uses a tiny, battery-powered camera worn in the frame of a pair of glasses that transmits visual images to an elastic garment that fits over the abdomen of the wearer. The wearer can receive vibrations from the more than 1000 electrodes in the garment that correspond to the visual images registered by the camera. Another such device transmits electrical impulses directly to electrodes implanted in the visual cortex of the brain. Initial tests of this system appear to be promising. Also available are devices to enable persons with retinitis pigmentosa to see at night.

A number of interface devices have been developed by Kafafian (1970). These include modified keyboards for electric typewriters that enable persons to use their feet, fists, or mouth to operate the typewriter. One interface uses a single control stick for this purpose, while another has split the typewriter keyboard into two 7-key devices, each of which could be strapped to an arm of a wheelchair; Kafafian has also developed a briefcase-size unit to be used for transmitting a visual display of the manual alphabet over the telephone so as to enable deaf individuals to communicate via this medium.

Devices that can be used to compress the rate of speech have been found to be effective with visually impaired children and those with severe reading problems (Short, 1972). These devices discard small fragments of the recorded speech and close up the gaps so that there are no distortions in pitch or quality, as one might find when speeding up a 33 1/3 rpm record to 45 or 78 rpm (Foulke, 1966).

A potentially significant interface for deaf persons is closed captioning. Norwood (1976) reported on research that showed that about 10 percent of ordinary television viewers find captions to be distracting. Consequently, a system has been developed that permits stations to caption television programs and broadcast them in such a way that the captions will not appear on the television screen unless a special decoding device is attached to the television set. The television watching of the deaf can thus be enhanced without infringing upon the television pleasures of the hearing. Efforts are now underway to encourage television stations to purchase the necessary captioning and encoding equipment. Decoding equipment will be available through commercial department stores.

In 1968, Sullivan, Frieden, and Cordery published a manual (now somewhat dated) that described numerous ways that the telephone can be modified for use by persons with a wide variety of physical disabilities. These modifications include the use of hands-free equipment, microswitches, amplifiers, card dialers, and other dialing and holding aids. Using these, persons who are disabled or restricted in their ability to travel could participate in educational programs or communicate with others through technological interfaces with the telephone system.

Several other interface devices are described in the proceedings of a conference on systems devices for the disabled (Foulds & Lund, 1976). These include aids for travel, eating, communication, and numerous other prosthetic and orthotic appliances.

Sixty-one different communications end-instruments are described in a report prepared by Skinner (1977). This useful document provides a narrative description of each device, a picture, and a check sheet that classifies each device along a variety of dimensions.

Recent hardware developments in communication aids have created problems in dissemination and instructional applications. Vanderheiden and Luster (1976) have suggested that priority be given to the following:

1. The generation and dissemination of cumulative information on the aids that already exist.
2. The development of projects to exemplify appropriate field uses of communication hardware.
3. The implementation of field evaluation for existing communication aids.
4. The refinement of existing aids rather than the development of new ones.

As the state of the art in microprocessing and electrical engineering continues to improve, it is anticipated that the handicapped will be major beneficiaries through the development of interfaces that will compensate for their disabilities. Several current developments appear to have particular potential for the field of education. It will be interesting to observe the progress that will be made in these areas during the coming years.

One such emerging technology is video discs. Video disc systems represent a dramatic change in storage and flexibility over present video systems. For example, a single disc costing less that $10 could record and store the *Encyclopedia Britannica* using only 4 percent of its available capacity; and 54,000 individual slides, each capable of being accessed randomly, could be stored on one side of a video disc. If the disc is used for storing motion pictures, one side of the disc can store 30 minutes of video programming. The disc's visual images can also be stored in combination with more than one audio track. For example, film (still or motion) sequences with two language tracks, one in English and one in Spanish, may be stored and accessed randomly. National marketing for such video disc systems was projected for late 1978 in the United States (Braun, 1978; Wood & Stephens, 1977). While marketing has been somewhat delayed, it appears that it will soon be a commonplace reality.

Braun (1978) reported that few educators are aware of the existence of video discs and that fewer still have given any thought to how they might use systems to improve the learning environments of their students. Among the few researchers who are investigating the use of video discs in education are Thorkildsen, Williams, and Bickel (1978). They are exploring the use of video disc technology with moderately retarded pupils.

Video graphics is another area of great potential. In the past, instructional programmers working with CAI who wished to use complex visual images had to have the computer connected to some prerecorded visual image system, such as a slide-projector (Cogen, 1969). Such visual

image systems resulted in considerably increased cost and decreased reliability of the total system. Now, through microprocessor technology, visual images can be stored and generated in the computer (Free, 1978). Although video graphics (sometimes called computer graphics) do not have the audio advantages of video disc systems, they nevertheless have considerable potential for educational applications with the handicapped, particularly with the hearing impaired and deaf populations.

Another development that will probably revolutionize telecommunications and related distribution systems is fiber optics (Whittaker, 1976). Coupled with laser technology, such distribution systems will vastly increase the number of audio messages or television channels that can be transmitted, and also improve their quality. For example, it would theoretically be feasible to transmit the entire contents of the 30-volume *Encyclopedia Britannica* in .10 second. A conventional pair of copper wires can handle up to 24 simultaneous phone calls, while 2 optical fibers can accommodate the equivalent of 33,000 such calls (Powell, 1977). If these distribution systems are eventually installed, the implications for the transmission of information through telecommunications, as discussed earlier, would be considerable.

SYSTEMS TECHNOLOGY

Gallagher (1970) has defined a system as a combination of elements functioning in relationship to each other. He has pointed out that we do not really have an educational system, according to this definition. We have an educational tradition that stresses autonomous units and self-contained operations rather than interactive, mutually responsive elements. In recent years, however, the field of special education has developed a number of subsystems that have the potential for being integrated into a larger educational system. Several of these will be discussed in this section.

Instructional programs

The implementation of PL 94-142 has, in one bold move, placed systems technology on center stage. The major operational component of PL 94-142 is the IEP (Abeson & Zettel, 1977). While there is a variety of uses of the term "program" in education, the definition of "program" in 94-142 is conceptually similiar to the systems technology concept of a program. This concept was stabilized in the late 1960's when the field of programmed learning shifted from its earlier emphasis on format

(Hofmeister, 1971). This switch has been described by Green (1967, p. 79) as follows:

> In looking into the future, it seems clear that the day of the classic self-instructional program, as it has come to be recognized in the past decade, is almost over. We have passed through the dark ages of controversy over such matters as whether a branching program is superior to a linear program, whether an overt response is necessary to the learning process, whether it is more or less desirable to incorporate small steps into a program, and whether people are pigeons.

Corey (1967), in clarifying the then new definition of an instructional program, listed the following elements: determination of objectives; analysis of instructional objectives; relevant population characteristics, e.g., entering behavior; evidence of success of instruction; and construction of the instructional environment. These elements are all present in the definition of an IEP, namely: statement of annual goals (for determination of objectives); short-term instructional objectives (for analysis of instructional objectives); present levels of educational functioning (for relevant population characteristics); provision for program monitoring and review (for evidence of success of instruction); and statement of services to be provided (for constructing the instructional environment).

The fact that a given procedure (e.g., use of IEPs) is consistent with systems technology does not necessarily make that procedure effective. There is, for example, considerable conflict in research findings related to the use of behavioral objectives (Crutcher & Hofmeister, 1975). Stolovitch (1978), in discussing the value of behavioral objectives, stated: "The special education technologist has a particular mission to assist in discovering what ways, if any, instructional objectives contribute to improved learning for the handicapped" (p. 36).

The major justification for the use of IEPs appears to be ethical and legal, and a substantial program-specific research base does not exist. In researching the impact of IEP procedures on math achievement with the mildly handicapped, Boehmer and Hofmeister (1979) were able to show gains in favor of IEP users versus nonusers. The range of research possibilities in this area has been somewhat reduced because the use of control groups of handicapped pupils would now be a violation of federal law.

A major contribution of the implementation of systems technology in classroom procedures will be the potential for blending research and practice (Lovitt, 1978). Instead of confining research procedures and projects to the researcher, the techniques advocated by Lovitt stress the involvement of the classroom teacher in the search for data to validate and modify classroom practices.

Instructional packages

The Commission on Instructional Technology (1970) noted that technology does not have to move people, it transmits the impact of people. One of the vehicles used in instructional technology to transmit impact is the instructional package. In reporting on the development and validation of a mediated package for training parents of preschool mentally retarded children, Hofmeister and Latham (1972) recommended further study of the use of mediated training packages as a practical method of treatment well within the resources of many agencies.

A *learning package* has been defined as a systemized way of delivering content and processes to a learner (Kapfner & Kapfner, 1972). The term *package* implies a self-contained and portable system. Most packages can, in fact, be sent through the mail. A package may consist of printed materials alone; however, many include slides, cassette tapes, videotapes, and films (Stowitschek & Hofmeister, 1975). Blackhurst and Wright (1978) illustrated how systematic computer approaches could facilitate planning for the development of instructional packages. A special education package must not only provide portability and systemized development and delivery of content and process, it must also be validated for a given population of handicapped persons. Only after validation with a specific target population should the term "packaged program" be applied in the strict instructional technology usage.

The approach to packaging that is having the most extensive impact in special education is one that stresses the use of relatively low-cost printed materials that give precise and practical instructions for teaching specific skills to given populations of handicapped learners. Such packages are considerably more generalizable when they are validated for use by paraprofessionals and parents (Thiagarajan, 1975). Examples of such packages include the *Training for Independence Series* (1977) and the *Project MORE Series* (1976).

Competency-based teacher education

One of the most significant forces that has affected special education personnel preparation during the 1970s is competency-based teacher education (CBTE). Blackhurst (1977) described a model for developing CBTE programs in special education and listed characteristics of such programs as follows:

1. Competencies that are required for any professional preparation program are publicly stated.

2. Objectives for the various educational experiences are stated in behavioral terms.
3. Criteria for evaluating when objectives have been met and competencies attained are specified and made available to students.
4. Alternative learning activities and multiple entry points are available to individualize the instructional program for students.
5. Where possible, time for completing instructional activities is variable, while achievement is held constant.
6. Instructors and students both share accountability for performance.

The parallels between these conceptualizations and those related to instructional programs for children (see above) should be obvious. Similarly, CBTE programs make considerable use of instructional packages in their delivery of the instructional program.

Implicit in competency-based approaches to teacher education is the obvious notion that students must have the opportunity to demonstrate the competencies that they have developed. Consequently, most CBTE programs have rather extensive field components.

Considerable efforts have been expended to identify and specify competencies for various special education professions, including teachers of the educable mentally retarded (Rotberg, 1968), special education curriculum consultants (Altman & Meyen, 1974), teachers of the secondary-level educable mentally retarded (Brolin & Thomas, 1972), special education supervisors (Harris & King, 1974), directors of special education (Anderson & Schipper, 1974), directors of special education resource centers (Blackhurst, Wright, & Ingram, 1974), clinical teachers (Schwartz & Oseroff, 1975), special education professors (Ingram & Blackhurst, 1975), teachers of children with learning and behavior disorders (Blackhurst, McLoughlin, & Price, 1977), teachers of the gifted (Altman, Faherty, & Patterson, 1978), teachers of the severely handicapped (Fredericks, Anderson, Baldwin, Grove, Moore, et al., 1977), teachers of the learning disabled (Newcomer, Magee, Wilson, & Brown, 1978), and elementary teachers involved in mainstreaming (Redden & Blackhurst, 1978).

Although these competency lists have some apparent validity, it should be emphasized that most have not been validated from the standpoint of whether they in fact make a difference. As Shores, Cegelka, and Nelson (1973) noted, this is one of the major tasks facing instructional designers who are involved with CBTE.

Once competencies and objectives have been developed, instruction can be delivered in a variety of media and formats. In addition to instructional packages (mentioned in the previous section), an array of alternatives has been used. Among these are CAI (Cartwright & Cartwright, 1973), gaming (Semmel & Baum, 1973), videotapes (Currie, 1976), microteaching (Shea & Whiteside, 1974), automated teacher-feedback systems (Semmel, 1972), adjunct autoinstruction (Renne & Blackhurst, 1977), alternative mediated formats (Donaldson & Martinson, 1977), modules (Blackhurst, Cross, Nelson, & Tawney, 1973; Wixson, 1975), multiplier effect models (Meyen, 1969), change agent models (Anderson, Hodson, & Jones, 1975), and contingency management systems (Tawney, 1972).

As Blatt (1976) has demonstrated, not all special education professors are supportive of CBTE. Nevertheless, more and more states are moving toward competency-based teacher certification and federal funding for training grants is contingent upon proposals that reflect competency-based programming. In addition to the references mentioned in this section, the interested reader is referred to the comprehensive treatments of CBTE in special education by Creamer and Gilmore (1974), Blackhurst (1977), Semmel, Semmel, and Morrissey (1976), and the special issues of certain journals that are completely devoted to the topic. These include:

Behavioral Disorders, 1976, *1* (2).
Teacher Education and Special Education, 1978, *1* (2).
Journal of Teacher Education, 1978, *29* (2).

Technical assistance systems

Since 1966, various technical assistance services have been available to special education teachers, administrators, and project personnel. Largely supported by federal funds, these services have ranged from the loan of instructional materials to computer-based information storage and retrieval. Originally, these services were provided by Special Education Instructional Materials Centers (SEIMCs). A special issue of *Exceptional Children* [1968, *35* (3)] provides a good overview of the original SEIMC Network.

Shortly after the SEIMCs were established, Regional Media Centers for the Deaf and an Instructional Materials Reference Center for the Visually Handicapped were added to the Network. A National Center on Educational Media and Materials for the Handicapped (NCEMMH) was also added (LaVor, Forsythe, Wexler, Duncan, & Milenson, 1969). Lance (1973) has written an overview of all of these projects and their services.

In 1974, the federal program that supported these various projects was reconceptualized. The program developed Area Learning Resource Centers (ALRCs), which provided technical assistance on media and materials, Regional Resource Centers (RRCs), which provided aid in diagnostic and prescriptive programming, and several special offices dealing with materials development and distribution. Coordination was provided by the NCEMMH and the Coordinating Office for Regional Resource Centers (CORRC) (Blackhurst, 1974).

Another federal program shift occurred in 1977, and the special offices, ALRCs, and CORRC were eliminated. The RRCs were relocated and took on the responsibility of providing technical assistance to the states in a variety of services related to the implementation of PL 94-142. These services included information storage and retrieval of professional literature (CEC, 1978a) and the availability of instructional materials on a national basis (Risner, 1978). Other technical assistance services have been available to support the efforts of early childhood special education projects, developmental disabilities projects, gifted and talented projects, leadership training projects, and others (Reynolds, 1974).

Although the various federally funded projects have provided many valuable services to the field, the potential for the development of a national special education network that could provide services on a coordinated basis was never fully realized. This is due, in large part, to the number of switches in program emphasis that have been made as well as an absence of a well-defined federal policy related to the development and operation of such services that was acceptable to top-level administrators. One of the long-term benefits that accrued from these projects is the existence of approximately 800 local centers providing technical assistance of various types to special educators located in different size geographical regions within the various states. These centers were primarily developed as a result of the efforts of the regional SEIMCs. Several information storage and retrieval systems are also now available as a result of developments in the original SEIMC network (Lance, 1977). The technology of technical assistance is now being continued and refined by such agencies as the Technical Assistance Development System (Clifford & Trohanis, 1976.)

Perhaps one of the most significant outgrowths of these federal technical assistance programs has been the development of a cadre of professionals who have acquired interest and competence in applying technology to the field of special education. In fact, as a result of the impetus primarily from persons who were involved with these earlier

projects, a new professional organization was developed. The Association for Special Education Technology (ASET) was organized as a national affiliate of the AECT (Cotzin, 1973). The major goals of this association are as follows:

1. To facilitate improvements and adaptations of materials for special education.
2. To stimulate development of new technologies for special education.
3. To identify and publicize unique instructional needs of special education.
4. To foster cooperation among special education and instructional technology interest groups.
5. To encourage the development and production of effective special education materials.
6. To promote improved federal legislation for technology in special education.
7. To assist in the placement of instructional technologists in special education.

In 1978, the first issue of the *Journal of Special Education Technology* was published by this organization to serve as the major vehicle for disseminating professional literature relevant to these stated purposes.

BARRIERS

Lance (1977) stated that the field of instructional technology has made more progress in the development of systematic approaches to instruction than in the use of nonhuman resources to improve education. He concluded that the gap between technological invention and adoption is due to several factors: (1) educators are conservative and view technology as too risky; (2) technology is perceived as a threat to jobs and personal interactions with children; (3) costs are too high; and (4) the vehicles for bridging the gap between the development of technology and its implementation are yet to be fully developed.

In addition to these, the following barriers to the implementation and greater use of technology were identified by some 75 experts who attended a national conference on technology in special education (Blackhurst, et al., 1979):

1. User needs for which the applications of technology have the greatest relevance have not been adequately defined.
2. There are insufficient data which compare the effectiveness of

programs delivered via machine and face-to-face programming.

3. Initial start-up and hardware costs are usually high.
4. Systems using telecommunications are most cost-effective when economies of scale have been realized.
5. There is a paucity of information concerning cost-effectiveness.
6. Good software is expensive and time consuming to develop.
7. There is a shortage of personnel who have the experience or education to provide quality programming.
8. Many decision makers and potential users have negative attitudes toward technology.
9. Equipment manufacturers are frequently not interested in working with educators because of perceived lack of profitability in educational enterprises.
10. Local authority is threatened when others develop curriculum content and control the delivery system.
11. Political and geographical boundaries frequently militate against the development of large-scale cooperative efforts.
12. Insufficient channels are available for most telecommunication systems. Regulation and licensing of these systems also impede the development of additional ones.

It should be noted that these barriers represent opinions and are not necessarily valid or based on empirically verified data. However, they do represent the thinking of many professionals who have been involved in educational technology. If there is validity to any of these perceived barriers, then it is obvious that they will need to be overcome if broader applications of technology in special education are to be realized.

CONCLUSION

Even in light of the aforementioned barriers, this review has prompted the authors to conclude that technology has played a valuable role in the education and habilitation of exceptional people and has the potential for playing an even greater role in these respects in the future. Gough (1968) has suggested that technology can and does contribute to the solution of many problems associated with deficiencies and limitations in educational services for the handicapped.

More recently, Lance (1977) predicted an even greater utilization of technology in order (1) to facilitate the integration of handicapped children into the least restrictive environment, (2) to help meet the needs of the severely handicapped, (3) to compensate for physical and sensory impairments, (4) to manage the development and implementation of IEPs, and (5) to respond to pressures to improve the educational system.

One additional concluding point should be emphasized: The great majority of the sources cited in this review represent descriptive articles. In general, there has been a paucity of research that has specifically attempted to assess the effectiveness of different technologies or their employment as alternatives to other approaches. Many of the conclusions that have been drawn concerning the application of technology to the education of the handicapped have been based upon logic more than empirical data. Future efforts should be devoted to the development of empirical studies that can be used as the basis for decision making relative to the development and use of the technological alternatives in special education.

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Senator **Hatch**. All witnesses' complete statements will be placed in the record, without objection.

Dr. Elder, we are delighted to have you here, and as Commissioner of Administration on Developmental Disabilities of the Department of Health and Human Services, we will really be interested in what you have to say.

[The biographical sketch of Dr. Elder follows:]

JEAN K. ELDER, Ph.D.

Commissioner on Developmental Disabilities
Office of Human Development Services
Department of Health and Human Services

Jean K. Elder, Ph.D., was sworn in as the U.S. Commissioner on Developmental Disabilities on January 25, 1982.

The Administration on Developmental Disabilities, which she heads, is an agency of the Office of Human Development Services, responsible for administering the Developmental Disabilities Act. The agency's mission is to ensure provision of services to an estimate 3.9 million severely disabled citizens in the United States, and to serve as the focal point within the Department of Health and Human services for issues and programs related to disabled people.

Dr. Elder, an educational psychologist, comes to the Department of Health and Human Services from Michigan, where she was an Associate Professor at Michigan State University and Northern Michigan University. She is the author of numerous publications in the field of developmental disabilities, mental retardation, and special education, and has lectured widely to State, national, and international audiences.

Dr. Elder was born in Virginia, Minnesota, on May 30, 1941, and raised in Marquette, Michigan. She holds Ph.D. (1969) and M.A. (1966) degrees in psychology from the University of Michigan. Her B.S. degree (1963) from the University of Michigan is in education. Post-doctoral work completed at the University of Wisconsin focused on administrative management, organizational development, and program development.

In 1976, President Gerald R. Ford appointed her to the President's Committee on Mental Retardation, where she served as a member of the steering committee. In 1978, she was elected a Fellow of the American Association on Mental Deficiency. She is also a member of the Council for Exceptional Children, the Association for the Severely Handicapped, and the National Association for Retarded Citizens.

In Michigan, Dr. Elder was active at the local and district levels of Zonta International, a service organization for professional and executive women, and in the P.E.O. Sisterhood, a philanthropic and educational organization interested in bringing to women increased opportunities for higher education. She was also named to the board of directors of the Child and Family Services, the Michigan Public Health Advisory Council, and the Michigan Bureau of Rehabilitation Advisory Council.

Dr. Elder has been cited for her achievements in *Outstanding Young Women in America* (1976), *Who's Who of American Women* (1977), and *Personalities of the West and Midwest* (1977). In 1974, she was initiated into Delta Kappa Gamma, an international society for women educators, and into Phi Delta Kappa, a national honorary fraternity in education recognizing professional achievement.

May 1982

Dr. **Elder**. Thank you very much, Senator.

Senator Hatch, Congressman Brown, before I begin I must say that I am delighted to follow a special education colleague with my testimony.

I truly appreciate the opportunity to appear before you on behalf of the Administration on Developmental Disabilities, Office of Human Development Services, Department of Health and Human Services, and to participate in this hearing concerned with technology and the handicapped.

The very able contributors to the document prepared by the congressional Office of Technology Assessment are to be commended for their comprehensive and detailed contents of the report.

The distinctions made in the report in defining the terms "impairment," "disability," and "handicapped" reflect the growing emphasis on functional abilities of individuals, the increasing role of technology in this field, and a sensitivity to the needs of individuals whose degree of disability and handicap may be significantly reduced by the appropriate application of technology.

The assertion that technology may be used to keep impairments from becoming disabilities and disabilities from becoming handicaps is an important aspect of the concept of prevention.

I have reviewed the document from a pragmatic as well as a program vantage point. While generally the discussion of the complexities of the service delivery system for disabled and handicapped individuals is thorough, there are three specific references to the developmental disability program which tend to obscure the intent of the Developmental Disabilities Act. The following changes are recommended:

The Omnibus Budget Reconciliation Act of 1981 which amended the Developmental Disabilities Act repealed section 110, the evaluation system. Thus the evaluation system referred to is no longer mandatory. However, those States in which evaluation systems have been developed are encouraged to continue their process and procedures. The description of section 110 in the document should be amended to reflect this legislative development.

Second, the Developmental Disabilities Act and title XX of the Social Security Act are described under the heading "Social Services." This appears to suggest that, like title XX, the major focus of the developmental disabilities program is the provision of services. This is not the intent of the Developmental Disabilities Act. The thrust of the DD program, unlike title XX, is that of planning and advocacy on behalf of the developmentally disabled, helping developmentally disabled individuals access generic and specialized services, and identifying and filling gaps and weaknesses in the service delivery system. Federal funds are not to be used to duplicate existing services. Rather, the limited money available to the States is used to help fill gaps where services do not exist.

Third, the last four lines of the statutory definition of developmental disabilities included in the text have been omitted in the appendix and should be added to the existing definition to read,

> And reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are lifelong or of extended duration and are individually planned and coordinated.

While this omission represents an oversight in editing, it also serves to highlight a major aspect of the uniqueness of the developmentally disabled population which the Administration on Developmental Disabilities is mandated to serve.

Not only do individuals in this group manifest a severe degree of functional limitations which are likely to continue throughout the individual's life, but the complexity of the impairment and the chronic and severe nature of the disability results in the need for a combination of specialized and interdisciplinary diagnostic treatment, care, and services, which are not always necessary for less disabled individuals.

As stated in the report, the OTA recognizes a broad definition of technology, which includes both hardware and process technology. Although the report attempts to limit its scope to technologies that are intended for and apply to individuals, much of the discussion in the report centers on product development, marketing, and diffusion. While advances in technological hardware present tremendous opportunities for many handicapped people, the focus of research which more significantly impacts on the developmentally disabled population includes direct service alternatives and service delivery systems, the process technologies rather than the product technologies. Little is mentioned of prevention, nonmedical intervention, and the new ideology of care for the developmentally disabled in the least restricted setting. These are research areas that are presently being addressed on behalf of the developmentally disabled and are supported through the special project authority. These technologies include and should continue to include treatment planning, the development of models of alternative living and social adaptations of the developmentally disabled. These advances have contributed greatly and continue to contribute to the independence, integration, and self-fulfillment of persons with developmental disabilities.

Applied research designed to promote more efficient and effective methods for delivery of services to persons with developmental disabilities and training of professionals and paraprofessionals to provide these services are addressed in the Administration on Developmental Disabilities through grants to university affiliated facilities [UAF].

The UAF's offer interdisciplinary courses on developmental disabilities and substantial clinical practicum experiences to students in a variety of disciplines. Programs include comprehensive training in etiology, diagnosis, and treatment of developmental disabilities and the needs of the developmentally disabled in education, vocational training, social development, cognitive development, communication, locomotion, and health. An interdisciplinary clinical training program assures the training of highly skilled specialists needed to serve the developmentally and also assures a greater degree of responsiveness by the generic professional who will encounter the developmentally disabled individual in his professional work.

In addition to regularly enrolled university students, UAF's provide a variety of short- and long-term training courses to individuals who are practicing professionals, paraprofessionals, and parents, as well as handicapped individuals themselves. Courses are designed in response to training needs expressed by communities in their effort to provide services to developmentally disabled people.

The UAF's have developed a cost-effective "train the trainer" technology in response to State agency training needs. This practice extends tremendously their impact on services to developmentally disabled people.

For example, UAF's have developed training packages for title XX and title IVB child welfare caseworkers, as well as training programs on management information systems for human services systems at the State and local level.

In summary, the UAF's have been successful in developing basic research and evaluation as well as providing effective training. These technologies and coursework models have focused on responding to a serious national challenge: How to produce service systems that are humane, responsive, functional, and cost effective. I am indeed proud to serve as commissioner of a program which is creative, which emphasizes coordination, and which has managed to bring research and technology to the direct service level in many States. The basic research and technology described in the OTA report and by my colleagues have been and will continue to be tapped for the developmentally disabled citizens in this country. However, the future of many of these individuals and the quality of their life is dependent on greater research utilization, technology transfer, and dissemination.

That concludes my remarks, Senator Hatch.

[The prepared statement of Dr. Elder follows:]

STATEMENT BY
JEAN K. ELDER, PH.D.
COMMISSIONER

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
OFFICE OF HUMAN DEVELOPMENT SERVICES
DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
AND THE
HOUSE SUBCOMMITTEE ON SCIENCE AND TECHNOLOGY
OF THE
COMMITTEE ON SCIENCE AND TECHNOLOGY

SEPTEMBER 29, 1982

Mr. Chairman and Members of the Committee:

I appreciate the opportunity to appear before you on behalf of the Administration on Developmental Disabilities, Office of Human Development Services, Department of Health and Human Services, and to participate in this hearing concerned with technology and the handicapped. The very able contributors to the document, entitled "Technology and Handicapped People" prepared by the Congressional Office of Technology Assessment, are to be commended for the comprehensive and detailed contents of the report.

The distinction made in the usage of the terms impairment, disability, and handicap, in the text, reflects a sensitivity to the needs of the afflicted individuals and the value of appropriate and timely application of technology to prevent an impairment from becoming a disability and a disability from becoming a handicap.

I have reviewed the document from a pragmatic as well as a program vantage point. In my role as Commissioner, Administration on Developmental Disabilities, it is important for me to identify interpretative and technical inaccuracies in reference to the Developmental Disabilities Program which tend to obscure the intent of the Developmental Disabilities Act. The following changes are recommended in order to reduce ambiguity.

- The last four lines of the statutory definition of Developmental Disabilities have been omitted and should be added to the existing definition contained in the appendix to read:

  "and reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are lifelong or of extended duration and are individually planned and coordinated."

- The Omnibus Budget Reconciliation Act of 1981, which amended the Developmental Disabilities Act, repealed Section 110 (evaluation system) thus evaluation systems are no longer mandatory. However, those States in which evaluation systems have been developed are encouraged to continue their process and procedures. The description of Section 110 in the document should be amended for this legislative development.

- The Developmental Disabilities Act and Title XX are described under the heading "Social Services." This appears to suggest that, like Title XX, the Developmental Disabilities program's major focus is the provision of services. This is not the intent of the

> Developmental Disabilities Act. The thrust of the DD program, unlike Title XX, is that of planning and advocacy on behalf of the developmentally disabled, helping them access generic and specialized services and filling gaps and weaknesses in the service delivery system. Federal funds are not to be used to duplicate existing services.

Much of the discussion on technology in the OTA document centers on product development. Although the report describes a problem with limited utilization and dissemination of developed products, it would be appropriate if the report cited techniques in research application. Little is mentioned of service delivery technology, prevention and non-medical interventions, and community alternatives to institutionalization. These are research areas being addressed on behalf of the developmentally disabled. The Developmental Disabilities program has supported technological advances through the Special Project authority particularly in the area of long term care because a large percentage of the target population are severely and profoundly retarded and have been or are currently institutionalized. These technologies include social development, therapeutic recreation, work technology products and devices, and other products developed in bioengineering laboratories. These advances have contributed greatly to the comfort, well being and functioning of persons with developmental disabilities.

The personnel issues identified as Issue 5 and Option 5A in Technology and Handicapped People appear to view personnel preparation in an isolated fashion. Instead, development of a training curriculum should take place at the time of technological research and development. When there are shortages in specialized fields such as physical therapy, the employment of "train the trainer" techniques or the training of a generalist may be more cost effective than endeavoring to use more funds to train individuals in the discrete speciality. A generalist who has received training in a variety of human service disciplines can be a far more effective case manager and, when necessary, can consult with a specialist in a special field to further enhance client management.

In addition, insufficient emphasis is placed on the "wellness" concept regarding training of personnel to provide services to handicapped individuals who are not medically vulnerable. The training of professionals from a variety of non-medical disciplines in the appropriate application of technologies should be considered as a fully effective option rather than a partial solution.

Option 5B, which discusses expanded use of volunteers, appears to have considerable value in terms of alleviating a personnel shortage. A variety of incentives would provide further impetus for volunteers from the private sector to aid the handicapped. However, before volunteers can contribute effectively to any program of service to the handicapped, they should be encouraged to commit consistent periods of time to this effort and also receive appropriate training when needed.

The research and training component of the Developmental Disabilities program is the University Affiliated Facility (UAF) program which is described in full, for the record, in an appendix attached to this testimony. The UAFs offer interdisciplinary courses on "Developmental Disabilities" to students in a variety of disciplines even if the students are not necessarily planning to work with the handicapped. This provides exposure to the nature and needs of the developmentally disabled in education, vocational training, social development, cognitive development, communication, locomotion and health. An interdisciplinary training program assures a greater degree of responsiveness by the professional in the event that a developmentally disabled individual becomes part of a generic case load. In addition to regularly enrolled University students, UAF's provide a variety of short and long term training courses to individuals who are practicing professionals, paraprofessionals and parents as well as handicapped individuals.

Continuing education for physicians, allied health professionals, special education teachers, and rehabilitation counselors are available through UAF's and focus on developmental lags, their remediation and service needs of the handicapped.

A cost effective "train the trainer" technology has been developed at some of the UAF's in response to State agency training needs.

One UAF has developed slide tapes for their course in Developmental Disabilities which includes a segment on "parental perspectives." This has been offered on educational television as well as in several departments at the particular University. Another UAF has developed a training package for Title XX and Title IVB child welfare caseworkers who have had difficulty in providing services to handicapped individuals. Still another UAF has developed an exemplary research and training program on data base and management information for human service systems.

Some of the UAFs have been quite successful in developing basic research and evaluation as well as providing effective training. These technologies and course work models have been entered into a data base system at the National Association of University Affiliated Programs which provides pertinent information to 43 UAFs around the country.

Perhaps one of the most significant technological advances developed at a UAF has been the development of Case Management for the Developmentally Disabled where the service needs are multiple and an array of generic and specialized services are accessed to meet the goals and objectives of an individualized habilitation plan. In one State where such a system was implemented, 240 services never available to the developmentally disabled were negotiated by the case managers.

I am proud to be associated with a program which is creative, emphasizes coordination and which has managed to bring research and technology to the service delivery systems in many States. The basic research and technologies described in the OTA report and by my colleagues have been tapped for the developmentally disabled. But the future of many individuals and the quality of their lives is dependent on greater research utilization, technology transfer and dissemination.

Mr. Chairman, this concludes my remarks. I will be happy to answer any questions you or the members of both committees may have.

APPENDIX
UNIVERSITY AFFILIATED FACILITIES (UAF) PROGRAM

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
OFFICE OF HUMAN DEVELOPMENT SERVICES

Program Purpose

. The University Affiliated Facilities form a national network of 47 facilities, 36 of which receive funding from the Administration on Developmental Disabilities, in 35 States which provide interdisciplinary training through exemplary service programs and biomedical, behavioral and programmatic research.

. UAFs serve individuals with complex disabilities for which services are not otherwise available, train professionals in their States and regions to promote proper diagnosis and treatmment in statewide services, and assist local and State planning and service agencies organize necessary services.

Brief History

. The legislative authorization for the UAF program originated in PL 88-164 with the project grants for the construction of university affiliated facilities for the mentally retarded. Under the construction authority, portions of nineteen of the current facilities were constructed at a total Federal cost of $41,553,000. The Federal Government holds a twenty year obligation, beginning with the completion of construction, that these facilities continue to serve individuals with developmental disabilities, as stipulated in Sec. 107, PL 95-602.

. The Developmental Disabilities Service and Facilities Construction Act of 1970 was an extension of earlier legislation, although it set a new pattern incorporating three major disability groups and focusing program resources on interagency coordination. For the UAF program, this meant funding for ten percent of the administrative and operational costs of the facilities. This was to provide the programs with base or core support on which to build a program with resources from other Federal, State and local sources.

. The two main funding sources for the program are the Developmental Disabilities Assistance and Bill of Rights Act for the core support grants and the training grants to institutions of higher learning from Title V of the Social Security Act as administered by the Bureau of Community Health Services, Office of Maternal and Child Health.

. The Administration on Developmental Disabilities provided operational and administrative funds to 36 facilities in FY 82 for a total of $7,238 million. The minimum core support grant is set at $150,000 in the current law, PL 95-602. The primary use of this core grant is for personnel costs, generally personnel with administrative or community service responsibilities.

. The Office of Maternal and Child Health provided the main source of UAF grant monies, $14,285,679 million in training grants to 19 UAFs, including one which is not supported by the Administration on Developmental Disabilities.

. Other sources of Federal funding are the Bureau of Education for the Handicapped, Vocational Rehabilitation, Title XX, and Title XIX. The grants from the Federal programs account for 39 percent of the total UAF network budgets of $105,485,712.

. In addition, the UAFs work with the National Institute for Child and Human Development supported Mental Retardation Research Centers to ensure that the latest possible knowledge is available through the service system. The UAFs provide a clinical population used by the MR Research Centers to test and to demonstrate new methods of treatment and prevention. The FY 82 funding level for the MR Research Centers is approximately $7 million.

Senator HATCH. We appreciate your excellent testimony, Doctor.

Congressman Brown, could you take over the gavel? I have to go back to the Senate. We are going to have a vote there.

We will turn now to Dr. Ozer, who is a professor of child health and development at George Washington University School of Medicine.

We are delighted to have you with us as well.

[The biographical sketch of Dr. Ozer follows:]

Mark N. Ozer, M.D.

Professional interests:

1) Development and implementation of planning systems for health services with particular reference to management of chronic illness and the treatment of disabled persons.

2) Development and implementation of personal health care procedures so as to lead to the enhancement of independent function by the recipient of services.

3) Development of evaluation criteria for health care services relating to health care as a resource development system.

4) Implementation through policy in the legislative and regulatory arenas of above.

Education:

M.D. Boston University School of Medicine 1957
B.A. Harvard College (History and Science) 1953 (cum laude)

Additional Training:

Medical Intern Stanford University Hospital 1957-58
Medical Resident Stanford University (S.F. General Hosp.) 1958-59
Neurology Resident Mt Sinai Hospital (New York) 1959-60; 1962-64.
Fellow, Walter Reed Army Institute of Research, Washington School of Psychiatry 1964-65.

Professional Experience:

1975- Present: Consultant to programs in mental health, disabled children and adults in program design, training, and establishment of ongoing evaluation systems. Consultant to Government agencies and Assoc. on policy and regulation. Medical practice in the treatment of chronic neurological problems.

1965-74: Director, Program for Learning Studies, Childrens Hospital National Medical Center, Washington, D.C.

Administered interdisciplinary research, training and treatment program focused on the development of new methods for the assessment of children with disabilities leading to planning for non-categorical services; models for service delivery leading to more efficient use of professionals; models for consumer involvement in decisions.
A "Collaborative Service System" was thus designed and implemented in sites throughout the US and abroad that served to integrate health, educational and social services as a model of more cost-effective services.

1960-62: Neurologist 7520th USAF Hospital, London, England.

Research and Special Project Experience: (as project developer and/or consultant on major component) Partial listing

1980 Major consultant on project "Technology and the Handicapped" for Office of Technology Assessment, US Congress.

1979-81: Consultant to Health Program of Mainstream, Inc. (non-profit) Design and implementation of model program for health care for handicapped persons in community hospitals. Development of manual for use by hospitals throughout the country.

1978-79: Design and implementation of training programs in 10 regions of the country for technical assistance for hospitals, nursing homes and health profession schools in implementation of civil rights of handicapped persons.

1979-81: Consultant to National Council on Aging for the design of planning conference, research program for the integration of handicapped persons and "at-risk" elderly persons into the mainstream of programs for elderly persons.

1979 Design and implementation of planning conference(s) on the application of technology to the problems of handicapped persons. American Assoc. for the Advancement of Science, National Sci. Found.

1979 Consultant on planning for the development of more effective services to handicapped persons at Hope Haven Childrens Hospital, Jacksonville, Florida; Western State Hospital, Staunton, Va; St Agnes Hospital, Baltimore, Md.; Florida School for the Blind and Deaf, St Augustine, Fla.

1978 Consultant on planning for services for handicapped Prince Georges' County, Md.; Howard County, Md.; Eau Claire, Wisconsin.

1977 Consultant on Health Care Program, Head Start, Abt Associates; Southeast Community Hospital Patient Education Program, Washington, D.C.; Title I Program Planning, D.C. PUblic Schools, Washington, D.C.; Prince William County Public Schools, Va.; Stamford, Connecticut Public Schools; Denver Childrens Hospital, Denver, Colo.; National Naval Medical Center, Bethesda, Md.

1976 Consultant to Health Care Issues, White House Conference on Handicapped National Childrens Center (retarded), Washington, D.C.; Hillcrest Childrens Center (mental health), Washington, D.C.; Houston Mental Health Services, Houston, TX; Northern Virginia Training Center (epilepsy control program).

1965- Design and implementation of coordinated services for health, education, and social services in Norfolk, Va.; Carroll County, Md.; Montgomery County, Md.; Kent County, Md.; District of Columbia; Louisville, KY; Tucson, Ariz.; Salem, Mass. among others.

Professional affiliations at present:

Associate Professor (Research) George Washington Sch. Med. Dept. Child Health and Development, Washington, D.C. Associate Professor (Clinical) Howard Univ. Sch. Med., Dept. Neurology, Washington, D.C.

Board of Editors Journal of Learning Disabilities, Behavioral and Brain Sciences.

Society for Neuroscience, American Acad. Neurology, American Acad. Aphasia, International Neuropsychology Society, American Educational Research Assoc.; Society for Behavioral Medicine, American Society of Cybernetics, Society for General Systems Research, D.C. Medical Society.

Licensed in District of Columbia, Maryland as physician

Publications (partial listing of recent publications from total of 50)

Solving Learning and Behavior Problems of Children: A Planning System Integrating Assessment and Treatment. Jossey-Bass, San Francisco, CA 1980

A Cybernetic Approach to Assessment of Children: Toward a More Humane Approach to Human Beings. Westview Press, Boulder, Colo. 1979. (editor)

Guide to Planning Implementation to Section 504 for Health Providers and Health Profession Schools. Office for Civil Rights DHEW National Institute for Advanced Studies, Washington, D.C. 1979

"The Evaluation of Brain Function as an Adaptive System" in The Systems Paradigm ed. C. Dechert. Franco Angeli Editore Milano, ITALIA 1978.

"Levels of Interaction in the Assessment of Children" in Research to Practice in Mental Retardation vol.-2 ed. P. Mittler University Park Press, Balt., Md. 1977.

"Assessment of Children with Learning Problems" in Reading Problems in Perspective ed. C. Peters Addison-Wesley, Reading, Mass. 1977.

"Enhancing the Family as a Planning Unit" in Systems Science and the Future of Health. Groome Center, Washington, D.C. 1976

Introduction to the Collaborative Service System. Program for Learning Studies, Washington. D.C. 1975.

"Diagnosis in Relation to Children with Learning Problems: The Use of Models" in Cybernetic Technique in Brain Research and the Educational Process. Am. Soc. Cybernetics, Washington, D.C. 1973.

Presentations:(partial listing of recent presentations)

"Problem Solving Assessment: An Interactive Process" International Neuropsychology Society 1979

"Problem Solving Planning Approach to Children with Learning Problems" keynote address Wisc. State Assn for Children with Learning Problems 1978

"Client Involvement in a Seizure Control Program" Am. Assoc. Mental Def. 1978

"A Human Resource Development System" Symposium on the Humanization of Assessment in Mental Health Programs American Assoc. for the Advancement of Science 1978

"Modeling of Nervous System Function as an Interactive System" Society for Neuroscience 1976

"Therapy as a Planning Process" Mental Health Research Institute Univ. of Mich. 1976.

"A Cooperative System for Child Development" American Instructors of the Deaf 1975.

"Handicapped Consumers and Section 504: Implications for the Effectiveness of Health Care" American Public Health Association 1980.

"History-taking with Patients: A Feedback Loop Engendering Health" American Assoc. for the Advancement of Science. 1981

"Planning with Patients: A Technology of Self-Help" Gerontological Society of America, 1981.

Dr. **Ozer**. Thank you, Chairman Hatch and Chairman Walgren and members of the committees. I welcome the invitation to offer testimony on the OTA report on Technology and Handicapped People, specifically in the area of the need for personnel trained to involve disabled people in the development, evaluation, delivery, and maintenance of technology.

I speak in my capacity as a physician trained in neurology who has functioned since 1965 in the actual provision of services for disabled children and their families, and I have been particularly concerned in my research and writings with the method by which physicians and other health professionals provide services for and to disabled persons. I speak in still another capacity as one of the special consultants to the health program of the Office of Technology Assessment in the initial planning and writing of this report.

As I stated before, I shall address the issues relating to the training of personnel for work in this field, but I am particularly interested in how such training could really be focused to deal with the involvement of disabled persons in the development and delivery of technologies. I have chosen to deal with these two issues so they may contribute to the solution of a third issue as defined in the OTA report—that is, the process of the appropriate development and evaluation of technologies.

I believe that the training of personnel to involve disabled persons in decisions about their use of technology is crucial if we are to use technology in a cost-effective manner. Decisions as to devices to be used for example are made in thousands of individual settings throughout the country and are again made throughout the lifespan of different disabled individuals to deal with differing needs. An important goal, therefore, of any adequate rehabilitation or habilitation program is a development within each disabled person and/or their surrogates of the ability to be an informed consumer of technology.

Like some of the other speakers I would like to emphasize what I think is an important distinction made in the OTA report between the various terms. The term "impairment," of course, as was described, is a physical loss or failure to develop certain functional bodily attributes. For example, an impairment would be weakness of the legs secondary to problems in the spinal cord. Such impairments would lead to what might be called "disabilities," where that term refers to the actual functional difficulties in life such as the inability to be mobile, to get around. It is such a person's interaction with a more or less hospitable environment that provides a third factor wherein technology has its greatest use. The environment may or may not provide what may be called "handicaps" to the ability of that person to function. Limitations in the design characteristics of wheelchairs, for example, the width of doorways, and the degree of incline of ramps are some of the handicapping factors wherein changes can be made so as to permit more optimal function.

As an example, I observed in the course of my medical work a young man with a recent injury to his neck who has weakness in both his legs and comparable weakness in his forearms which make it difficult but not impossible for him to push his own chair. He is particularly frustrated about his inability to propel the wheelchair he had been issued over even the slightest incline in the flooring, or to propel himself up the rather long but slight incline between his hospital ward and the setting in which he gets his physical therapy.

The front-wheel characteristics of his wheelchair handicapped him, given that he had weak arms and could not get enough momentum going to overcome the incline. The addition of a relatively simply antirollback device enabled him to retain his hard-won gains in going uphill. He could then do it in stages rather than roll back entirely when he was unable to go the entire distance.

This device worked for this man in accomplishing what was for him an important goal in his being able to function more independently. The device is a simple one. What is perhaps more difficult is the means by which the need for this device was identified and the device thus appropriately provided. Technologies, whether of a hardware nature such as this antirollback device, or in the form of training and other services, are not in themselves perhaps good or bad. The degree to which any technology actually works is a result not only of the degree it deals with the handicaps of that environment, but the degree to which it fits into the personal goals of that individual.

The question I would like to present and address is how can professionals function to make this fitting process more effective? How can professionals function to enable disabled persons to contribute to the solution of their problems and grow in their ability to be informed consumers of technology over their lifespan as their needs may change? How can professionals be trained to include the disabled person in the selection process so that the technology will indeed meet his or her needs? I suggest therefore the development of the ability to define goals and contribute to design and modifications of technology necessary to accomplish those goals is in itself a technology, albeit a set of procedures or "soft" technology rather than the more commonly understood use of this term. I suggest that the procedures for planning for individual technological requirements and for the involvement of disabled persons in planning for their own needs is a major relatively untapped resource enhancing the effectiveness of all services for the disabled.

The newly disabled person in the hospital, for example, does not ordinarily have the experience to function independently in the selection of devices and does so generally on the recommendation of the professionals. Decisions are made for patients in light of their presumed needs, yet ultimately these same persons must learn to care for themselves and participate in the design, modification, and repair of the technology for their own use to an increasing degree outside the hospital.

The goals of rehabilitation treatment both for the newly disabled and for ongoing care require rethinking. Some ordinary goals, for example, are for the paralyzed person to learn to push his own wheelchair, to learn to transfer from bed to chair, to learn to drive a car, and so forth. A complementary set of goals must be clearly defined as even more basic to the habilitation or rehabilitation process. Some such new goals are for the person to be able to define his needs clearly, to state his problems and the outcomes he or she might be seeking.

In the case of the young man described earlier the fact that he was able to express his concern about going uphill and state that as one of his short-term goals made it possible for that simple antirollback device to have considerable effect at relatively low cost. Even more helpful is the ability of the disabled person to become aware of the multiplicity of strategies or means that worked for him in order to learn to transfer or to push his chair or whatever the goal was in the more traditional sense in rehabilitation. Those actions that permitted those outcomes to occur are frequently actions that may be useful in a multitude of situations. Gradually the newly disabled person becomes more aware of those actions that work for him or her, that there are a number of such actions, and that such actions are ones that he or she have taken. He or she becomes more aware of their own resources in the form of ideas that work for them. The person's resourcefulness makes the design and modification of technologies appropriate to the individual needs. In aggregate, enlisting the resourcefulness of the thousands of disabled persons would make the entire system for delivery of technologies far more cost effective.

It becomes more crucial therefore in my opinion to review the planning, decisionmaking process as in itself a technology—a way of doing things that is subject to development and evaluation, just as any hardware-type device might be so subject.

It becomes necessary to train those professionals who work with the disabled in the process of sharing responsibility for planning and to be more explicitly aware of the importance of development of these skills in the disabled person complementary to those goals that are ordinarily set.

I should like now to address some of the legislative or other remedies that may be available to enhance this already existing commitment on the part of professionals working with the disabled. The various laws dealing with the Federal interest in services for the disabled: The habilitation of the developmentally disabled, the education of handicapped children, and the rehabilitation of those with physical or mental impairments all in their present state require an individualized planning process. This is a requirement in each of these laws. This requirement is a breakthrough in moving toward more functional procedures for defining needs and possible outcomes. There have been a number of problems in the implementation of these requirements, as documented in the body of the OTA report, most particularly in chapter 3. But I suggest that these new approaches must be supported and strengthened in any subsequent revision of these laws.

Even more innovative and in my opinion even more likely to improve the cost-effectiveness of technology is the requirement in each of these laws for the involvement of disabled persons or their surrogates in the planning process.

The difficulties in the implementation of this even more far-reaching concept are also documented in the body of the OTA report. However, these beginning efforts should be recognized as an opportunity for the solution of many of the issues that would make it possible for the resourcefulness of all concerned to be involved to truly meet the promise of technology. Such promise cannot be realized by professionals alone, but only in concert with those for whom they work. It becomes more clearly a primary task of professionals to engender and recognize the contributions of disabled people in planning for their own needs.

This concludes my testimony.

[The prepared statement of Dr. Ozer follows:]

Testimony

Senate Committee on Labor and Human Resources

House Subcommittee on Science, Research and Technology,

Committee on Science and Technology

29 September 1982

Mark N. Ozer, M.D.
Assoc. Prof. Child Health & Dev.
George Washington Univ. Sch. Medicine
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Washington, D.C. 20008

I would like to testify today in relation to three of the salient issues stated in the OTA Report on Technology and Handicapped Persons. I speak in my capacity as a physician trained in neurology who has functioned since 1965 in the actual provision of services for disabled children and their families. I have been concerned with the mode by which physicians and other health professionals provide services for and to disabled persons. I speak in still another capacity as one of the Special Consultants to the Health Program of the Office of Technology Assessment in the initial planning and writing of the Report.

I shall address the issues relating to the training of personnel for work in this field. I shall relate that issue to how such training could begin to deal with the involvement of disabled persons in the development and delivery of technologies. I have chosen to deal with these two issues so that they may contribute to the solution of the problems defined in the OTA Report as a third issue - that is, the process of the appropriate development and evluation of technologies.

I believe that the training of personnel to involve disabled persons in decisions about their use of technology is crucial if we are to use technology in a cost-effective manner. Decisions as to devices to be used are made in thousands of individual settings throughout the life span of the different individuals with disabilities to deal with changing needs. An important goal therefore of any adequate rehabilitiation program is the development within each disabled person of the ability to be an informed consumer of technology.

I think it is important at this point to emphasize, as in the OTA Report, the distinctions to be made between the various terms in use. The term "impairment" is a physical loss or failure to develop certain functional bodily attributes. For example, an impairment would be weakness of the legs secondary to problems in the spinal cord. Such impairments would lead to what might be called "disabilities" where that term refers to the actual difficulties in life such as an inability to be mobile, to get around. It is such a person's interaction with a more or less hospitable environment that provides a third factor wherein technology has its greatest use. The environment may or may not provide what may be called "handicaps" to the ability of that person to function. Limitations in the design characteristics of wheelchairs, the width of doorways, and the degree of incline of ramps are some of the handicapping factors wherein changes can be made so as to permit more optimal function.

An example I observed recently may illustrate these issues. A young man with a recent injury to his neck has weakness in both his legs and some weakness in his forearms which make it difficult but not impossible for him to push his own chair. He is particularly frustrated about his inability to propel the wheelchair he had been issued over even the slightest incline in the flooring or to propel himself up the rather long but slight incline between his hospital ward and his physical therapy setting. The front wheel characteristics of his wheelchair handicapped him given that he had weak arms and could not get enough momentum going to overcome the incline. The addition of a relatively simple anti-rollback device enabled him to retain his hardwon gains in going uphill. He could then do it in stages rather than roll back entirely when he was unable to go the entire distance.

This device worked for this man in accomplishing what was for him an important goal in his being able to function more independently. The device is a simple one. What is perhaps more difficult is the means by which the need for this device was identified and the device thus appropriately provided. Technologies, whether of a hardware nature such as this anti-rollback device, or in the form of training and other services are not in themselves good or bad. The degree to which any technology actually works is a result not only of the degree it deals with handicaps of that environment but the degree to which it fits into the personal goals of the individual. How can professionals function to make this fitting process more effective? How can professionals function to enable disabled persons to contribute to the solution of their problems and grow in their ability to be informed consumers of technology over their life span as needs change?

The development of the ability to define goals and contribute to the design and modifications of technology necessary to accomplish those goals is in itself a technology albeit a set of procedures or a "soft" technology rather than the more commonly understood use of this term. I suggest that the procedures for planning for individual technological requirements and for involvement of disabled persons in planning for their own needs is a major relatively untapped resource in enhancing the effectiveness of all services for the disabled.

The newly disabled person in hospital does not ordinarily have the experience to function independently in the selection of devices and does so generally on the recommendation of the professionals. Decisions are however made for patients in light of their presumed needs yet ultimately these same persons must learn to care for themselves and participate in the design and modification of technology for their own use to an increasing degree outside the hospital.

The goals of rehabilitation treatment both for the newly disabled and for ongoing care requires rethinking. The ordinary goals are for the person to learn to push their own wheelchair, to learn to transfer from bed to chair, to learn to drive a car and so forth. A complementary set of goals must be clearly defined as even more basic to the rehabilitation process. Some such new goals are for the person to be able to define his needs clearly: to state his problems and outcomes he is seeking. In the case of the young man described earlier, the fact that he was able to express his concern about getting uphill and state that as one of his short term goals made it possible for that simple device to have considerable effect at relatively low cost. Even more helpful is the ability of the disabled person to become aware of the multiplicity of strategies or means that worked for him in order to learn to transfer or to push his chair or whatever. Those actions that permitted those outcomes to occur are frequently actions that may be useful in other situations. Gradually, the newly disabled person becomes more aware of those actions that work for him; that there are a number of such actions; and that such actions are ones that he himself has taken. He becomes more aware of his own resources in the form of ideas that work for him. The person's resourcefulness makes the design and modification of technologies appropriate to the individual's needs. In aggregate, enlisting the resourcefulness of the thousands of disabled persons would make the entire system for delivery of technologies far more cost-effective.

It becomes more crucial therefore to view the planning, decision-making process as in itself a technology - a way of doing things that is subject to development and evaluation just as any hardware type device. It becomes necessary to train those professionals who work with the disabled in the process of sharing responsiblity for planning and to be explicitly aware of the importance of these goals complementary to those ordinarily set.

I shall now like to address some of the legislative or other remedies that may be available to enhance this already existing commitment on the part of professionals working with the disabled. The various laws dealing with the Federal interest in services for the disabled: the habilitation of the developmentally disabled, the eduation of handicapped children, and the rehabilitation of those with physical or mental impairments all require an individualized planning process. This requirement is a breakthrough in moving toward more functional procedures for defining needs and possible outcomes. There have been a number of problems in the implementation of these requirements, as documented in the body of the OTA Report. These new approaches must be supported in any revision of these laws.

Even more innovative, and in my opinion potentially even more likely to improve the cost-effectiveness of technology, is the requirement in each of these laws for the involvement of disabled persons or their surrogates in the planning process. The difficulties in the implementation of this even more far reaching concept are also documented in the body of the OTA Report. However, these beginning efforts should be recognized as an opportunity for the solution of many of the issues that would make it possible for the resourcefulness of all concerned to truly meet the promise of technology. Such promise cannot be realized by professionals alone but only in concert with those for whom they work.

Mr. **Walgren**. I wonder if I could just ask the panel quickly, what percentage of the people that you see in rehabilitation have immediate prospects of constructive involvement with the work-related world? What percentage?

Dr. **Hofmeister**. As far as the special education population in schools, you are looking at approximately 80 percent moving into either part- or full-time employment, providing they get the right training and support services.

Mr. **Walgren**. What about physically handicapped?

Dr. **Ozer**. I think it varies considerably with the degree of impairment. What I am suggesting in my testimony is that the way we go about the rehabilitation may enhance their capability of solving the real problems they would have in functioning in the work force. That very process of planning for whatever their needs may be at any one time can enhance that sense of resourcefulness and the ability to function effectively. It is not a given in any particular case.

Mr. **Walgren**. You indicate that one of the great areas for progress is the involvement of the resourcefulness of the disabled themselves. If there is no real rewarding or constructive involvement in the work force ahead of them, do you think that they will be encouraged to be resourceful in overcoming their handicaps?

Dr. **Ozer**. Well, what I am suggesting is the way we go about treating people can enhance the likelihood that they could be resourceful in terms of functioning in the work force. The ability to care for oneself I think is an important goal in any rehabilitation program, and the ability to do so at any level of independence is, I think, more likely to be created depending on how we work with people. Given the degree of impairment, we might not accomplish quite as much as with lesser degrees of impairment. I think a very important part of the degree to which one can maximize function lies in the degree to which disabled people feel themselves participating in their own planning: Becoming better able to define what their goals might be and what are some of the ways they have of accomplishing those goals.

Mr. **Walgren**. Do any other members want to add a comment?

Mr. **Brown**. Mr. Chairman, could I just offer a comment? I think the question you have asked is extremely important and the answer to it will always be conditional because of the intangible factors involved. I have had the opportunity, for example, to visit the wards in hospitals specializing in spinal cord injury where I noted quadriplegics paralyzed from the neck down who were still motivated to carry on occupational activity, and did so with considerable success. The key factor was first motivation, and then the technical assistance required to implement that motivation. The degree of injury was almost immaterial, given the other factors involved. The disabled can be a productive part of the workforce.

Mr. **Walgren**. But to get them motivated to design a solution to their own problems they would have to see the goal they are trying to achieve. I personally wonder whether we are in a situation where we are rehabilitating people, but for what? Simply to function is not quite enough, although I am sure that could be a motivation. I have seen people in independent living circumstances where they can function, but there is not anything for them to function.

Mr. **Brown**. I am sure you have seen a lot of quite well people in the same situation.

Mr. **Walgren**. What really troubles me is that I think there is a prevailing attitude in our society of unconcern about whether any individual functions well. We are sort of given the right to fail or not fail in this society. My personal view is that we do the disabled a great disservice by really having nothing for them to do after we enable them to live independently. What troubles me is that we may be thinking too much about getting them involved in designing ways to overcome their handicaps, while not providing them with the most important motivation which is something constructive for them to do, and the knowledge that there is something constructive that they can do, and that they would be appreciated for.

Dr. **Hofmeister**. I think a wealth of opportunities exist that we have not even touched upon as far as high-status employment is concerned. Maria Montessori in 1911 said at the start of the industrial revolution that at this time physical prowess would be relatively irrelevant in our society, that with the technological development, prowess in the society would be based on technological skills. And the computer terminal as an example opens up a wealth of opportunity, and those people for example leaving our institution with the ability to work at a terminal are starting around $30,000 to $40,000.

Mr. **Walgren**. You know it strikes me—and again this is a personal view—we have invested a great deal of money in our society in overcoming architectural barriers, and that is certainly a constructive thing to do, but if there is not any reason to go anywhere, what is the point? And the truth is that without the training that would enable the disabled to work in a satisfying way so that they get some appreciation for their contribution to the living world, have we really done them a service?

Dr. **Hofmeister**. I think what we are looking at is a distinction between functioning in society and a high-quality existence in society, and I think there are aspects of the technology that are going to open up exciting possibilities for those sort of things that we have not even begun to conceptualize, let alone plan for and train our personnel to prepare for.

Mr. **Walgren**. Thank you very much. We appreciate the contribution of the panel. We will look forward to working with your recommendations and we hope we can make something happen from them.

I want to welcome you all to the panel. Let me also say that your written testimony will be made part of the record regardless of your presentation, and so if you want to diverge from what you may have submitted in writing to add certain emphasis or communicate in a way that you feel is more effective, please feel free to do so. We will then have both your verbal testimony and anything in writing you would like to submit.

Let me start then with Dr. Aller.

[The biographical sketch of Dr. Aller follows:]

Dr. James Aller

Dr. Aller joined the National Science Foundation in 1975 as Program Manager for instrumentation and has held various research administrative positions since that time. Dr. James C. Aller was the acting Program Manager for the Science and Technology for the Handicapped Research from its inception in early fiscal 1979 until July 1979 when Dr. McNeal was appointed. He resumed program responsibilities in March 1981. He is also acting Program Director for the Quantum Electronics, Waves and Beams Program.

Prior to joining N.S.F., Dr. Aller for two years was a senior associate in a small business firm, Ketron, Incorporated. Previously, he was Associate Professor of Clinical Enginering in the George Washington University School of Medicine. Research interests are computer based systems particularly for use in measurement control and clinical medicine. Recent book articles concern clinical engineering, ultrasound instrumentation, and biosaline research.

From 1968 to 1970, Dr. Aller held the Chair of Physical Science at the Naval War College, lecturing on topics in military management, operations research, and systems analysis, acting as a consultant for various war games, as well as supervising student research. He was an operations analyst and section head in the Center for Naval Analysis from 1962 to 1968 in the Command Control Section. As a Naval Officer, he was gunnery officer on a destroyer, torpedo plane pilot, and specialized in missile systems.

Dr. Aller was born in Yakima, Washington. He graduated in 1942 from the U.S. Naval Academy, received a Master's degree in 1949 in applied mathematics from Harvard University and a D. Sc. in Biomedical Engineering from George Washington University in 1968.

Dr. Aller resides with his wife in Great Falls, Virginia, and has five children and five grandchildren.

He is a fellow of AAAS, senior member of IEEE, member of the New York Academy of Science, and of the Washington Operations Research/Management Science Council.

STATEMENTS OF JAMES ALLER, DIRECTOR, SCIENCE AND TECHNOLOGY PROGRAM TO AID THE HANDICAPPED, NATIONAL SCIENCE FOUNDATION, WASHINGTON, D.C.; JAMES RESWICK, SPECIAL ASSISTANT TO THE DIRECTOR, NATIONAL INSTITUTE OF HANDICAPPED RESEARCH, WASHINGTON, D.C.; MARGARET GIANNINI, DIRECTOR OF REHABILITATIVE ENGINEERING R&D SERVICE, VETERANS' ADMINISTRATION, WASHINGTON, D.C.; AND COLIN McLAURIN, ENGINEERING DIRECTOR, UNIVERSITY OF VIRGINIA, REHABILITATION ENGINEERING CENTER, CHARLOTTESVILLE, VA.

Dr. ALLER. Thank you, Mr. Chairman, for this opportunity to address the joint committee. I will skip over the written testimony which is a part of the record and go to the high points.

The first thing is that I think fundamentally the report that has been prepared is a major step forward, and it is difficult to do anything but commend it. I would like to make two comments on the two issues in which I feel I have some contributions to make.

The first one has to do with the involvement of the handicapped, and our observation when we attempted to involve that community in the planning of the program at the National Science Foundation, when we asked the American Association for the Advancement of Science to put together a series of workshops to at least explore the possible objectives of a science and technology program.

We discovered something that we all know, which is that there is a diversity of needs, and the different parts of the handicapped community see their priorities somewhat differently, and the easiest way to see that is in something you have alluded to in the way of architectural barriers. When you remove the curbs and make it a little easier for the wheelchair-bound community to move around and also the normal people with baby carriages, you also find that other parts of the handicapped community get into difficulty. Particularly those with obscured vision have trouble finding the edge of the street, so you have to be careful when one sets forth a program that uses advice from the handicapped to search for certain commonalities. We attempted to do that, and I personally think successfully, by trying to find common foundations on which one could base the designs relevant to differing handicaps.

Another example is one particular small project that I think many people who participated in can feel very proud. The particular project was conducted by Johns Hopkins University. Now there the objective was to look for a common technological base, which has been alluded to by several preceding speakers, in this case the personal computing capabilities, and there is one thing I felt very good about. We have over 900 inventors in the United States, most of whom I did not know about and who had not previously surfaced, thus this contest evoked to what amounts to a very interesting innovation base. I am very happy I was not among the judges, because I would have had trouble picking the top winners. Now you can see from this competition that it is possible to go from a common technological base and branch out from that base, in a way that can help many different kinds of disabilities.

I move on then to the next issue, which is issue five, having to do, in my interpretation, primarily with evaluation. I would like to make a point that in evaluations when they are conducted you have really a forward and a backward movement. In the case of our research program we put in a mode of what I would call evaluation of the information we were providing through a series of workshops that the American Association of Sciences conducted, the most recent one being in Wisconsin, where they examined the multiple uses of the personal computer. Now from this workshop we also find that present knowledge is inadequate, and one can redirect some of the research.

Second, as you look forward we can take note of a recent technological forecast in the National Science Foundation managed in quite a different group from the one I represent. What they found was that by 1990 there is every prospect that the computerized society that we are a part of is going to move to the point where one can conduct a great part of their work in their home environment if they so wish, a great blessing to those handicapped who have limitations of movement. When you look at the new graphic terminals, you are led to a question. For example, one can see these special images with translucent things in the foreground as part of the display. How are we going to use those kinds of terminals to continue to maintain the position of the blind professionals who have been able to participate in the computer software industry as it now exists? Of course technological forecasts need not be true of additional factors are possible. I interpret from what I have just said that that is a challenge to the research community to figure out a way around the potential barrier imposed by computer graphics.

The computerized home with the ability to be a workshop is going to happen. The question is how to exploit it.

Now returning again to my fundamental comment, I have nothing but praise for the report that I have been asked to address. I hope you will interpret my remarks as just sort of a fine-tuning on a couple of the points that were made.

[The prepared statement of Dr. Aller follows:]

STATEMENT OF
DR. JAMES C. ALLER
PROGRAM DIRECTOR, SCIENCE AND TECHNOLOGY TO AID THE HANDICAPPED
NATIONAL SCIENCE FOUNDATION
BEFORE THE
SCIENCE RESEARCH AND TECHNOLOGY SUBCOMMITTEE OF THE
HOUSE SCIENCE AND TECHNOLOGY COMMITTEE
AND THE
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
SEPTEMBER 29,1982

Mr. Chairman and members of the House Subcommittee and Senate Committee: The NSF Science and Technology for the Handicapped program is relatively small. It is designed to complement the research programs of National Institute of Handicapped Research, and programs of other agencies and groups funding such research. From working with a wide range of researchers and the handicapped, we believe NSF has gained a perspective important to addressing research which may improve the technology for aiding the handicapped.

However in FY 1983 we are planning to reorient our program. As our Director, Dr. Slaughter already described to you in the NSF authorization hearings before your Subcommittee on March 4, 1982:

> "Given the limited resources available to support this fundamental engineering research and the prioirty attached to it by myself and the National Science Board, we felt that applied proposals for work related to the physically handicapped should compete directly for support with other proposals in engineering. Such a step is in keeping with our more general reorganization of applied research in the Spring of 1981.

> We have phased out the targeted program in FY 1983 and made these applied research proposals eligible to compete for funds across all engineering programs. This really broadens the possible base of support for them while assuring that our funds are used to support the best engineering research proposals. I am certain that you will be pleased to know that several such proposals have already been funded as continuations or new starts in one or another of our engineering programs."

The Office of Technology Assessment's report, the subject of these hearings, provides the major policy issues to be addressed. This morning, I will discuss two of them. One is the diversity of handicapped persons needs and its implications for research. The other involves improvements in evaluation criteria used to define the goals of research programs and to assess the outcomes of research.

Comments on Issue 2 - Involvement of Disabled People

Let me address first the diversity of needs. Before the NSF program was begun, the American Association for the Advancement of Science (AAAS) brought together at a workshop a number of handicapped persons and researchers to suggest a research agenda. The workshop results were of great value in developing the objectives of NSF's program and were published in 1979 for wider use. The document suggests there is a wide divergence of opinion among the many different groups of handicapped persons as to how science and technology should be harnessed to assist the handicapped. Setting priorities with the assistance of these groups is an extremely difficult, if not impossible task. A simple example of the difficulty can be drawn from our everyday lives. The modifications to sidewalk curbs for wheelchairs, helping persons in wheelchairs to cross streets, increase the difficulty for blind persons in locating the curbs.

The NSF research program attempts to resolve such problems by striving to find a common science base from which individual adaptations can be made. The program has addressed this goal in two ways. First, it supports research to lay the science and engineering foundation upon which designers can base devices relevant to differing handicaps. It also has sponsored a competition designed to stimulate inventors and designers to develop devices using a common scientific or technological base.

Most of NSF's activity in S&T for the Handicapped supports research to develop the base of science and engineering upon which innovators and designers can build. This support issues not only from the S&T for the Handicapped program but also from several disciplinary programs in NSF. An example can be found in the work of Dr. Donald G. Childers at the University of Florida. His research may lead to visual presentations to aid the deaf in learning to speak more naturally. The research also will provide a base of knowledge of vocal fold vibration that can be used for other purposes, such as synthesized speech for robots.

The competition I mentioned a moment ago was based upon the many years of computer development and the microelectronics revolution which have provided low-cost devices with a variety of software programs. NSF sponsored the nation-wide competition to encourage and inspire ideas, devices, methods, and computer programs to help handicapped persons cope with difficulties in work, home, and community settings. The well spring of inventiveness ready to be harnessed in this country can be seen from the Johns Hopkins "First National Search for Applications of Personal Computing to Aid the Handicapped," complete in November 1981.

There was enormous diversity in the 900 applications but all used one concept, the personal computer. The three top winners were: Dr. Harry Levitt, a professor of speech and hearing sciences at City University of New York for a hand-held communicator for the deaf; Dr. Mark Friedman and his colleagues at Carnegie-Mellon University, who developed an eye-activated communicator for the speech-impaired; and Robin L. Hight of St. Louis, Missouri, who developed a lip-reading primer that duplicates mouth movements on a video screen.

Comments on Issue 3 - Research, Development and Evaluation of Technologies

The second issue I wish to address is the emphasis of the OTA report on evaluation. At NSF, the S&T for the Handicapped program views evaluation of its program by the handicapped as a dynamic source of guidance and critique. As I said earlier, we planned the NSF program goals and management techniques with input from handicapped persons who attended the AAAS workshop. We established a panel of handicapped persons to assist in the selection of awards. Many of our technical peer reviewers are handicapped persons.

Recognizing that the situations of handicapped persons are dynamic and that their needs and opportunities change, NSF has provided for a sustained evaluation of research priorities. The NSF program is designed to avoid a static, one-time research agenda. The AAAS has provided regional forums for researchers, designers, and handicapped persons to exchange information and recommend research priorities. The AAAS distributes the results through newsletters and provides us opportunities to modify NSF's research agenda.

The OTA Report seems to imply that Issue 2 on Involvement of Disabled Persons and Issue 3 Research, Development and Evaluation of Technologies can be separated. For editorial purposes this presentation is sound. Still, there is a continuing requirement to refresh the input of the handicapped throughout the course of research and in this sense incorporate evaluation as an intrinsic part of the research program.

I would like to comment on the following language in the OTA report: "Whether a disability becomes a handicapped depends upon the interaction of the disabled person with the physical and social environments surrounding that person." Technology creates both new opportunities for the handicapped and sometimes can convert disabilities into handicapping conditions. As an example, advances in computer technologies may positively benefit people with limited mobility but negatively benefit blind people. Technology forecasts and assessments should take these multiple impacts into account. One example is a technology assessment, undertaken for the NSF by the Institute for the Future in Menlo Park, California, addressed the impact of two electronic systems in the U.S. over the next 10 to 20 years. The systems, called videotex and teletext, provide means of widespread dissemination of textual and graphic information by wholly electronics means for display on low-cost terminals. There are obvious implications for expanding employment of persons with limited mobility.

Yet, as this technological advance enters our society, we may see a related computer advance limited employment for the blind. Here I refer to computer graphics which render obsolete some of the alphanumerical approaches of the past. Presently, we do not know how to solve this puzzle which provides new research targets. What seems clear is that attention in evaluation should be given to changes in technology, so that evaluation results are not outdated as technology changes employment. For this reason, NSF would reinforce the statement on page 21 of the OTA summary suggesting attention to the expected results of research. We would add that some technological forecasting is essential so that the evaluation may become more sophisticated than is sometimes the case.

Mr. Chairman, this concludes my preposed testimony. I will be pleased to answer any questions that you or other members of the Committee may have.

Mr. DYMALLY [presiding]. Thank you very much, Dr. Aller. Because we have so many witnesses today, we are trying to minimize the questions and answers.

We will proceed with the next witness. Dr. Reswick, please identify yourself for the record.

[The biographical sketch of Dr. Reswick follows:]

JAMES B. RESWICK, SC. D.

Dr. James B. Reswick returned to the Massachusetts Institute of Technology after service in the South Pacific during World War II to continue graduate studies in mechanical and electrical engineering concentrating on theoretical problems in automatic control. His doctoral studies and first publications were in this field. His interest and skills in electro-mechanical design led to faculty positions in the MIT Design Division in the Mechanical Engineering Department.

After a year as a Post Doctoral National Science Foundation Fellow at the Imperial College, London, England, in 1959 he returned to MIT and began to bring orthopaedic design problems into his student project courses. In 1960 he moved to Case Institute of Technology (now Case Western Reserve University) in Cleveland, Ohio, as Professor of Engineering and founding director of a new Ford Foundation funded Engineering Design Center. While this Center was created to involve graduate students in real engineering projects in automatic control and instrumentation, in 1962 Dr. Reswick began to develop federally sponsored research projects that applied engineering design to the problems of the physically disabled. His group developed the first computer controlled, externally powered arm to enable a high-level quadriplegic to manipulate his environment. While technical problems and teaching absorbed his major attention, realizing the importance of rehabilitation medicine, he established close working relationships with physicians and allied health persons at the Western Reserve School of Medicine and the Lakeside and Highlandview Hospitals.

In 1970 seeing a better opportunity to assume a leadership role in the then maturing field of rehabilitation engineering, he moved to the Rancho Los Amigos Hospital in Los Angeles, Calif. At Rancho he founded the first federally supported Rehabilitation Engineering Center and joined the faculty of the University of Southern California as Professor of Bio-medical Engineering and Orthopedic Surgery. Under his direction, with Dr. Vernon Nickel, Chief of Surgery as Codirector, the Rancho Rehabilitation Engineering Center focused on Functional Electrical Stimulation as a technique to improve the therapy of paralyzed persons and to provide them with long-term functional assistance. Many innovations for the treatment of stroke, spinal and head injury, cerebral palsy, and scoliosis were made during the 10 years of his leadership.

In 1980 Dr. Reswick resigned from Rancho Los Amigos Hospital and arranged a leave of absence from the University of Southern California to accept a position as Associate Director for Technology of the National Institute of Handicapped Research of the U.S. Department of Education in Washington, D.C.

Among his national and international leadership positions, Dr. Reswick has been president of the Biomedical Engineering Society and was founding president of the Rehabilitation Engineering Society of North America. He was elected to membership of the National Academy of Engineering and the Institute of Medicine of the National Academy of Sciences. For his "contributions to biomedical and rehabilitation engineering," he was awarded an honorary Doctor of Engineering Degree by Rose Polytechnic Institute and the grade of Fellow in the Institute of Electrical and Electronics Engineers.

Dr. Reswick is deeply concerned with the technical and social issues that separate the promise of technology to mitigate the handicaps of disabled persons from the ability of the manufacturing and service systems to deliver this technology to those in need. His present position at the National Institute of Handicapped Research enables him to influence national policy for most federally sponsored research on improving the quality of life of handicapped persons.

Dr. Reswick has authored or co-authored over 80 publications in the fields of automatic control, engineering design and rehabilitation engineering.

Dr. RESWICK. I am James Reswick, Special Assistant to the Director of the National Institute of Handicapped Research, an Institute Congressman Brown had a good deal to do with the creation of, and Dr. Spencer here was the first Acting Director. The first Direc-

tor, Dr. Giannini, is sitting at the table as well. Mr. Darld Long is now Acting Director.

I am very privileged to appear before you and discuss the report on "Technology and Handicapped People." It is an excellent report. It raises many issues. I wish I could talk about a number of them, but with the limited time I will focus on just one, and that has to do with the issue of evaluation of technology.

The issue is summarized on page 83 of the report as follows:

> A coherent, adequately funded, and well-focused program of evaluation is necessary at all levels of technology diffusion and adoption. Such a program does not currently exist in the disability-related technology sector.

I think this is an important issue, and I agree completely with the conclusion.

We have heard the word "evaluation" used two or three times today in another context. We are talking now about evaluation of technology. It is simply the determination of the degree to which a device meets the need of a handicapped person.

There are three significantly different types or classes of evaluation. The first one is technical evaluation—that has to do with mechanical or electrical testing to determine if the device does what it is supposed to do, life testing, and, most important of all, testing for hazards and for safety.

The second level of evaluation is internal clinical evaluation. This relates to the fact that it is not until the device is first tried in the clinic on a patient that many aspects of the problem not recognized in the beginning become clear and the possibility of stating nearly complete design specifications becomes real. This process, internal clinical evaluation, is vitally necessary, but often lacking.

I am reminded of Thomas Edison's first invention, the automatic vote counter, that he worked very hard on. It passed the technical evaluation beautifully, but he did not subject it to clinical evaluation, so when he presented it to the Congress it was rejected. He had not really studied the need of the customer for whom he was doing his research. He learned a lesson and he never made that mistake again, I am sure.

The third kind of evaluation has to do with external clinical evaluation. This is perhaps the most important phase. In the United States most new devices will come under the cognizance of the Food and Drug Administration. Classification levels require different degrees of clinical effectiveness and safety data, but all require some reliable test and evaluation process. Meeting requirements can be expensive and time consuming, but beyond just satisfying a Federal agency, evaluation is important to the manufacturers' market success.

The market for devices for the handicapped defies quick and easy analysis. A device must fit a person's lifestyle and be more cost effective than another solution, to be accepted by him or her and be authorized for payment by a third party. Every person is different, and his or her personal needs are different. The challenge to a new device is to meet enough needs of enough persons to permit quantity production and distribution.

Evaluation in the clinic or in the community is the only way to gain a meaningful measure of the likelihood of success of a device, and the indications for its application or feedback on changes that might lead to success. Effective evaluation, both technical and clinical, is a highly scientific process. Technical evaluation requires sophisticated test equipment with test protocols designed by high-level engineers. Considerable skill and knowledge are required to predict all failure modes and to set performance criteria that will result in a cost-effective device.

Clinical evaluation is equally demanding of scientific expertise, often requiring a combination of medical and technical experts. Usually a number of centers are involved in evaluating a new device on patients or clients. This requires a protocol that leads to statistically significant and scientifically objective results. Management of an evaluation program is challenging, and requires dedicated full-time staff. Poor evaluations are worse than none at all, as they may lead to devices becoming established in a delivery system that disappoint the user, can waste large amounts of money and possibly be dangerous.

Let me conclude with some remarks about what can be done now.

I believe the time is particularly appropriate to create a national rehabilitation technology evaluation program to be established jointly by the Veterans' Administration and the National Institute of Handicapped Research. I would point out that there exists the Interagency Committee on Rehabilitation Research that is legislatively mandated to cover all of the agencies that deal with all issues in rehabilitation for the handicapped, and as members of this committee, the VA and NIHR have been actively collaborating for a number of years.

Why are these two organizations most appropriate to take the lead? NIHR is mandated by its legislation to promote effective delivery of technology to handicapped persons, and has required evaluation activity in its research center program. It formally announced a priority entitled "Stimulation of Industry and Evaluation of Technology" that it is going to fund this year at the level of some $500,000.

The Veterans' Administration is the largest centralized purchaser of technical aids for the handicapped in the Nation. The VA Central Office Rehabilitation Research and Development Service, directed by Dr. Giannini here, after the NIHR, is the largest national R&D program for the handicapped. The VA systems of hospitals and medical centers is ideal for extensive clinical evaluations. Its procurement system requires effective evaluation of technological devices and systems purchased for veterans.

So the need for evaluation exists strongly in the VA. They have the system for doing the job. The National Institute of Handicapped Research has a mandate also to be deeply involved in evaluation, and is actually going to be funding some priorities in this area. However, NIHR has a very broad spectrum of research to fund, so they cannot alone adequately deal with the issue of evaluation.

I believe that the issue can be solved within the agencies but that Congress can, through its oversight and through perhaps the designation of specific funding, make a significant difference in the enhancing of this process.

[The prepared statement of Dr. Reswick follows:]

Testimony of James B. Reswick, Sc.D., Senior Scientist,
National Institute of Handicapped Research/OSERS,
Department of Education, before the Senate Committee
on Labor and Human Resources and the House Subcommittee
on Science, Research, and Technology of the Committee
on Science and Technology, September 29, 1982

Chairman Hatch, Chairman Walgren, and
Members of the Committees:

I am privileged to appear before you in support of the need to apply contemporary technology for the alleviation and rehabilitation of handicapped people, and to respond to the truly excellent report "Technology and Handicapped People" prepared by the Office of Technology Assessment.

For 20 years my professional life as an Engineering Professor and Research Director has been devoted to research and development of devices to aid the handicapped. As one of the very few persons to be elected to both the National Academy of Engineering and the Institute of Medicine of the National Academy of Sciences, I have gained significant national and international recognition for my Rehabilitation Engineering activities. Two years ago I accepted the offer of the Director of the National Institute of Handicapped Research, now part of the Department of Education, to become her Associate Director of Rehabilitation Engineering and Technology. I am now Special Assistant to the Acting Director of this organization.

While all the issues dealt with in the OTA report are of interest and concern to me, I wish today to focus on the one that I believe represents the greatest problem area of technology for the handicapped and which is most susceptible to change for the better. This is the issue of Evaluation of Technologies that is dealt with in the report on pages 75-83 and is defined as Issue 3 on pages 21-22 of the Summary.

THE ROLE OF EVALUATION IN TECHNOLOGY FOR HANDICAPPED PERSONS

Evaluation in the field of Technology for the Handicapped is simply the determination of the degree to which a device meets the needs of a handicapped person. Three distinct types or levels of evaluation should be considered:

1. Technical Evaluation:

   Technical Evaluation requires scientific testing and/or expert analysis of the mechanical, electrical, materials, etc., factors that relate to technical performance, safety, and failure modes of a device. It is concerned with the quality of the engineering design and the potential for maintaining the highest standards of quality control in production and subsequent maintenance.

2. Internal Clinical Evaluation:

   At the inception of a new design/development project, it is virtually impossible for any one person clearly to state specifications of a device to meet a patient's need. An initial attempt can be made by an effective team that includes medical, engineering, allied health, and technical professionals. Such a medical engineering team can set down initial performance goals and proceed from these goals to define research and development tasks. Still, the inescapable fact remains that it is not until the device is first tried in the clinic on a patient that many aspects of the problems not recognized in the beginning become clear and the possibility of stating nearly complete design specifications becomes real. This process--Internal Clinical Evaluation--is vitally necessary, but often lacking.

Inevitably, the first prototype must be redesigned and redeveloped, and it is seldom that only one cycle of this process is required. Rather, the process becomes a continuous one, with new and improved models being worked on and evaluated. It often is difficult for a developer to accept that his designs must be frozen for production at a time when he is still working on various improved versions, but at some point, a manufacturer must reach a decision that a product or a device has attained a level of development sufficient to warrant production and distribution for profit. It is absolutely vital that this occur if the firm or agency is to be able to encourage a continuing R&D effort in the first place.

3. External Clinical Evaluation

The third evaluation phase--External Clinical Evaluation--now becomes critical. In the United States, most new devices will come under the cognizance of the Food and Drug Administration (FDA). Classification levels require different degrees of clinical effectiveness and safety data but all require some reliable test and evaluation process. Meeting requirements can be expensive and time consuming. But beyond just satisfying a Federal agency, evaluation is important to the manufacturer's market success.

The market for devices for the handicapped defies quick easy analysis. A device must fit a person's lifestyle and be more cost-effective than another solution to be accepted by him and be authorized for payment by a third party. Every person is different and his personal needs are different. The challenge to a new device is to meet enough needs of enough persons to permit quantity production and distribution.

> Many highly motivated inventors create solutions for handicapped persons with whom they are personally involved only to discover that no broad market potential for their device exists. Evaluation--in the clinic or in the community--is the only way to gain a meaningful measure of the likelihood of success of a device and the indications for its application or feedback on changes that might lead to success.

A manufacturer of devices for the disabled faces a significantly more costly design, development, and marketing situation than do most deliverers of technological devices. But costs themselves are not the major problem. It is the risk engendered by the inability clearly to define the market potential of a new device that is the major barrier to industrial commitment in this field. What can be done to reduce this risk?

The first and most often stated need is for Government to "stimulate" industry by subsidizing early R&D and tooling costs through either direct grants or purchase of first production units at prices that include these costs. In the United States, such programs have been carried on by the National Science Foundation (NSF) (direct grants) and the Veterans Administration (VA) (prototype purchase). Other agencies, including the National Institute of Handicapped Research (NIHR), are seriously considering such assistance. But while subsidy seems to offer a relatively quick and easy solution (when funds are available), I do not believe it overcomes the fundamental problem of market risk. If a device truly meets a need for enough handicapped persons, it will succeed and costs will be covered. The "better mousetrap" needs no subsidy.

What is needed is an effective evaluation capability on a national scale. Let us examine in more detail what evaluation really means.

Effective evaluation--both technical and clinical--is a highly scientific process. Technical evaluation often requires sophisticated test equipment with test protocols designed by high level engineers. Modern materials, advanced electronics and computer technology are increasingly employed in new devices for the handicapped. Considerable skill and knowledge are required to predict all failure modes and to set performance criteria that will result in a cost-effective device.

Clinical evaluation is equally demanding of scientific expertise often requiring a combination of medical and technical experts. Usually a number of centers are involved in evaluating a new device on patients/clients. This requires a protocol that leads to statistically significant and scientifically objective results. Testing methods, data to be collected, criteria for selection of patients/clients, and form of reports--methodology, data, results, discussion and conclusion--all must be planned and carried out by skilled and knowledgeable professionals of high ethical and scientific competence.

Evaluation is often expensive and time consuming. For results to be credible and useful, scientific planning and execution are required. Management of an evaluation program is challenging and requires dedicated full-time staff. Poor evaluations are worse than none at all as they may lead to devices becoming established in a delivery system that disappoints the user, can waste large amounts of money, and possibly be dangerous.

Presuming that the manufacturer is successful in producing a useful technical product for the handicapped, he then faces some additional problems not usually encountered in distribution of non-medical devices. His devices normally are prescribed by a patient's physician or allied health professional. This means that the prescriber must be educated and trained in the application and use of the devices. Such training and education are costly and the prescriber must be completely sure of the performance of the device before he can fulfill the ultimate responsibility that professional ethics require of him. Thus the device development must usually occur in the context of a respected teaching-clinical facility if reported clinical experience is to be considered reliable by the prospective prescribing health service community.

Here again, evaluation plays the central role. Professional journals will only accept results that have been clinically validated. Information on which education and training is based and information to providers and consumers must be reliable and specific as to performance and the details of a person's handicap for which it is applicable.

A further problem facing the manufacturer is the fact that no electromechanical device ever improves with use and age. These devices inevitably require maintenance and repair, and the manufacturer must often assume responsibility for this service. The establishment and maintenance of such a service in a limited market may well be too costly to justify. Therefore, many small firms with limited marketing, distribution, and service capability refrain from producing rehabilitation engineering devices even though many have the technical capability and interest.

Evaluation is again important for it is in the field trials that potential repair and replacement needs are discovered. Some require redesign while others, because of cost factors, are accepted to be dealt with through maintenance and repair. The manufacturer must then plan his overall system to prepare for these needs. The very familiar systems supporting the automotive and appliance industries illustrate this issue.

A NTIONAL REHABILITATION TECHNOLOGY EVALUATION SYSTEM

> "A coherent, adequately funded, and well-focused program of evaluation is necessary at all levels of technology diffusion and adoption. Such a program does not currently exist in the disability-related technology sector."* (emphasis added)

I concur totally with this most important conclusion of the OTA study. But to create such a system is not easy. It is far more costly than usually estimated and its need is not well understood. However, while operational costs will be high, I believe that effective evaluation is a valuable component of a product's final cost and that most evaluations can and will be paid for by the private sector. The elements of a potential system are now in place. All that is needed is a clear concept and a good beginning.

I do not propose a great institute filled with people and laboratories, although some in-house testing capacity will be needed. Rather, I suggest that two or more relatively modest centers, each having coordinating functions with information storage and dissemination capability, are all that is required to make a beginning. Resources abound throughout the Nation to carry out clinical and community evaluations. What is needed is effective program management to ensure that protocols are scientifically designed, that patient and/or client groups are accurately and uniformly specified, and that data and reports are consistent and objective. They would soon become centers of information and should have a number of dissemination modes (e.g., a direct "800" telephone, computer network, frequent evaluation bulletins, comprehensive reports, and other innovative uses of communications systems). They would become places to which consumers, providers, authorizers, manufacturers, and government agencies at all levels could turn for immediate answers and continuing information updates.

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*Conclusion statement of Section 7 "Evaluation of Technologies," p. 83, OTA Report "Technology and Handicapped People," May 1982

Were such a system of centers to exist with a moderate accumulated history, manufacturers would have access to data on the nature of unmet needs, a way to determine the true potential of a new device and a source of data to develop credible information for many purposes. These are valuable commodities and represent legitimate components of a product's final selling price. Thus, a national evaluation capability can and should become self-sustaining.

RECOMMENDATION FOR ACTION

The National Institute of Handicapped Research (NIHR) is mandated by its legislation (PL 95-602) to promote the effective delivery of technology to handicapped persons, has required evaluation activities in its Research Center Program and has formally announced a priority entitled "Stimulation of Industry and Evaluation of Technology" for which the Secretary of the Department of Education intends to fund at least one Rehabilitation Engineering Center at an amount up to $500,000 in its FY 1983 Handicapped Research Program.

The Veterans Administration (VA) is the largest centralized purchaser of technical aids for the handicapped in the Nation. The VA Central Office Rehabilitation Research and Development Service funds (after NIHR) the largest national R&D program for the handicapped. The VA system of hospitals and medical centers is ideal for extensive clinical evaluations. Its procurement system requires effective evaluation of technological devices and systems purchased for veterans. Comprising a large and structured market component, it commands the attention of producers of technology for the handicapped. The VA, for many years, carried on an evaluation program primarily through its Veterans Administration Rehabilitation Engineering Center in New York City, an activity that has recently been de-emphasized.

The VA and the NIHR have collaborated for years in their respective R&D programs and they are formally linked through the legislatively mandated Interagency Committee on Handicapped Research and its Subcommittee on Rehabilitation Engineering. But the national need for an effective rehabilitation technology evaluation system is far greater than can be met by the NIHR and the VA as presently constituted or planned. NIHR's mandate for research covers all rehabilitation areas—leaving little of its research funds for an expanded evaluation effort. And, unlike the VA, the NIHR has no service delivery function. The VA has not yet reorganized its own evaluation program following the reduction in effort in the New York VA Rehabilitation Engineering Center.

I believe the time is particularly appropriate to create a National Rehabilitation Technology Evaluation Program to be established jointly by the Veterans Administration and the National Institute of Handicapped Research. Most of the planning and decision issues fall within the VA and the Department of Education and can be dealt with through the Interagency Committee on Handicapped Research which has the potential to examine possible roles of the Bureau of Standards, NASA, and other Government agencies as well. But it will require the attention of the Congress to facilitate action and to provide additional specific funding for this designated purpose.

This suggested approach, designed initially around the needs and capabilities of the Veterans Administration, is intended to serve the civilian sector as well. Once the kernel of the system is planted, it will grow and be nourished mainly by the private sector with the capability to serve both public and private agencies. I believe the potential of the proposed plan to become a truly National Rehabilitation Technology Evaluation Program exists. It is not the only approach, but I believe it is the most cost-effective way to deal with this important unmet need of handicapped persons.

Mr. BROWN [presiding]. Thank you very much, Dr. Reswick.

We will next hear from Dr. Giannini.

[The biographical sketch of Dr. Giannini follows:]

CURRICULUM VITAE OF MARGARET JOAN GIANNINI

Margaret J. Giannini, M.D., F.A.A.P. is presently the Director of the Rehabilitation Research and Development Service with the Veterans Administration, Washington, DC.

Dr. Giannini was the first Director of the National Institute on Handicapped Research. A part of the U.S. Department of Education, the Institute was Congressionally mandated by P.L. 95-602 (The Rehabilitation Comprehensive Service and Developmental Disabilities Amendments of 1978). Dr. Giannini a Pediatrician, and the former Director and founder of the Mental Retardation Institute of New York Medical College was appointed by President Jimmy Carter to this post on November 8, 1979. She was confirmed by the U.S. Senate on January 29, 1980, and sworn into office at the White House cabinet-room by Secretary of Education Shirley Hufstedler and Mrs. Rosalyn Carter officiated, on March 11, 1980.

As the founder and director of the Mental Retardation Institute, it should be noted that this was the first and largest facility for the mentally retarded and the developmentally disabled of all ages and etiologies in the United States and the world. She established one of the first University-Affiliated Facilities at New York Medical College under P.L. 88-164. Since 1950 she has been a pioneer in creating programs in diagnosis, treatment, education, research, training professionals, rights and affairs of the mentally retarded, developmentally disabled and the handicapped. Her involvements are manifold and encompass all levels, including international, national, federal, state and local matters.

Nationally, Dr. Giannini has held two of the most prestigious presidencies of organizations concerned with the mentally retarded, developmentally disabled and the handicapped. She is past President of the American Association on Mental Deficiency, an organization representing 12,000 members throughout the United States, Canada and eight national and four international affiliations. She is past President of the American Association of University-Affiliated Programs, an organization of directors and administrators representing over 75 university affiliated facility programs throughout the United States. She has been actively involved as a member of the National Committee of Children with Handicaps of the American Academy of Pediatrics, Chairperson of the Committee on Children with Handicaps of District II of the American Academy of Pedicatrics, created the Prevention Committee of the American Association on Mental Deficiency, Chairperson of the Nominations and Elections Committee of the American Association on Mental Deficiency, was appointed by the United Nations the Inter-regional Advisor on Mental Retardation and Developmental Disabilities. She has also been appointed Special Consultant to the Mental Retardation Construction Unit of the National Institutes of Health, Vice President for Medicine of the American Association on Mental Deficiency, Consultant by special invitation to the President's Committee on Mental Retardation on Early Screening for Prevention, and a member of the Scientific Advisory Board of the Kennedy Child Study Center (NYC).

On the state level, she included among her activities membership of the Advisory Council, System of Advocacy for the Retarded of the New York State Association for Retarded Children, member of the State Council for Developmental Disabilities; Chairperson of the Planning Committee of the State Council for Developmental Disabilities; member of the Honorary Committee of New York State Special Olympics; Chairperson of the Mental Retardation Task Force for State Wide Planning for Vocational Rehabilitation Services for the New York State Education Department appointed by Governor Nelson Rockefeller; member of the Advisory Committee of Retarded Infant Service; State Chairperson of the Committee for Handicapped Children of the American Academy of Pediatrics; and many more. She was also a member of Governor Rockefeller's Children's Committee of the New York State Department of Mental Hygiene.

Dr. Giannini is involved as advisor, member or chairperson of numerous local, city, county, community committees and organizations.

Dr. Giannini is the recipient of many awards from varying organizations in recognition of her professional and humanitarian services and achievements. She was saluted by the Association for Pediatric Research, selected "Woman of the Year" for Achievement in Medicine by AMITA, received Honorary Recognition for Achievement from the American Women's Medical Association, received Wyeth Medical Scientific Achievement Award, selected "Woman Doer" by Mrs. Lyndon B. Johnson at a White House Reception, received Enrico Fermi Education Award, received Women of the Year Award from the Westchester Federation of Women Association, Variety Club Women held a "Day in Honor of Doctor Giannini", received the first Honorary Degree, Doctor of Humane Letters, presented by Mercy College, received Bronze Medal for Developmental Checklist, awarded by the American Academy of Pediatrics, and awarded the Key to the City of Bologna, Italy and others. She belongs to numerous professional societies and associations, such as the American Women's Medical Association, American Medical Association, Amerian Academy for Cerebral Palsy, American Association on Mental Deficiency and American Association of University Affiliated Programs. She has authored and co-authored numerous publications and has presented many lectures, papers, keynote addresses, participated in panel discussions and workshops throughout the United States and the world.

CURRICULUM VITAE

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EDUCATION:
Boston University, 1940
Temple University, 1942
Hahnemann Medical University, 1945

PROFESSIONAL TRAINING:

Internship:	New York Medical College, 1945-1946
Residency:	Pathology, New York Medical College, 1946-1947
Residency:	Pediatrics, New York Medical College, 1947-1948

LICENSES AND SPECIALTY BOARDS:
National Board of Medical Examiners, 1945
New York State License, 1945 #45864
Washington, DC Medical License, 1979 #2630
Diplomate of the American Academy of Pediatrics, 1950

Dr. **Giannini**. Thank you very much. Mr. Chairman. I, too, appreciate this opportunity to appear before this joint committee hearing and comment on the Office of Technology Assessment report. This is of particular interest to me, since I have devoted 36 years of my life as clinician and researcher, professor, and administrator, to serving handicapped persons nationally and internationally.

As Dr. Reswick alluded, I was privileged to be the first director of the National Institute on Handicapped Research.

Initially I, too, would like to commend the Office of Technology Assessment for this report. It certainly offers a great deal of creativity and innovation which clearly, if implemented, could serve as a vehicle for the betterment of the quality of life for our Nation's estimated 45 million handicapped persons.

The report very adequately combines the goals, objectives, and concerns of multiples of people—the research experts, consumers, rehabilitation agencies, and other Federal agencies.

I would like to focus my remarks on just several issues, and those would be the ones I feel we can realistically respond to regarding the improvement of the quality of life for the handicapped.

Dr. Reswick very adequately stressed the problem of evaluation, and I concur with that, and feel it is a very important issue. However, I also feel that one of the problems is in the development and distribution of the technological processes. We have not very successfully served the disabled because we have not been able to complete the cycle of a concept of technology through the research, development, evaluation, manufacturing, and marketing circle.

I do not think that I need to more than allude to the fact that the Veterans' Administration has long been involved and been an outstanding contributor in the care of the disabled. I am very pleased to say that our Administrator, Mr. Robert Nimmo, and our chief medical director, Dr. Donald Custis, have consistently emphasized rehabilitation research and clinical care as a very high agency priority.

The report correctly identified marketing and diffusion of disability-related technology as a major concern of researchers in this area.

In my own area of rehabilitation research and development I recognize this is a serious problem, and we in the VA have initiated an interagency agreement with the Minority Business Development Agency in the Department of Commerce so that we can more swiftly disseminate research and development accomplishments and encourage the involvement of small business manufacturers.

In the report the option presented for Congress to "amend current legislation to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies" and the options for Congress "to charter a private organization or establish a joint, public-private corporation to provide marketing and production related services to both the private and the public sectors" offer some exciting possibilities for involving the private sector in producing and marketing technical aids for the handicapped, and I would subscribe to that notion.

However, we must recognize that there still remains a large gap between the researcher, the manufacturer, and the consumer, and possibly there may be some initiatives that could serve as possible inducements to industry to help close this gap in the way of tax incentives and other advantage items they could be involved with.

The other issue that we have not been able to convince industries of is the possible spillovers from the technology for the disabled that could well serve nonhandicapped people, that they could utilize and perhaps have a lucrative return.

Another effort perhaps should be encouraged for the early entry of industry in projects of research and development so that manufacturing could occur in a shorter period of time.

Another issue in the report that is well-taken is available information of technology to the consumer, and perhaps we should encourage more of the printed media, audio-visual, telecommunications, workshops, and conferences. It is well established that the consumer should be involved in all short- and long-term planning, and this would be an important part in the closure of the loop in getting technology to the consumer.

In the VA we are very sensitive and supportive of consumer involvement, and we make a concerted effort to have representation on all of our review boards, In our own particular merit review board of rehabilitation research we have six service organizations that are represented.

In the personnel issues in the report, a very important factor is manpower training. We have tried to address ourselves to this in the VA, in supporting rehabilitation engineers, because they are a very important part of the clinical service program in meeting the needs of disabled veterans.

In conclusion, the influence of technology I think you will agree is felt in nearly every dimension of the lives of all disabled people. As of August 1982, of the 30 million veterans, 3,100,000 were disabled, that we know of, that are receiving compensation and pension benefits from the VA. The overall problem in getting technology to the consumer is due to a set of very complex issues which must be addressed in a very careful way.

Again may I comment on the report in that I feel it does a real service in identifying problems regarding technology and handicapped persons, and presents some interesting approaches and options which must be considered and thoroughly explored.

Thank you for the opportunity to present my remarks.

[The prepared statement of Dr. Giannini follows:]

STATEMENT OF
DR. MARGARET J. GIANNINI,
DIRECTOR, REHABILITATION R&D SERVICE
DEPARTMENT OF MEDICINE AND SURGERY
VETERANS ADMINISTRATION
BEFORE THE
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
AND THE
HOUSE SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY
OF THE
COMMITTEE ON SCIENCE AND TECHNOLOGY

SEPTEMBER 29, 1982

Mr. Chairman,

I appreciate your invitation to appear before this joint committee hearing to review the Office of Technology Assessment Report on Technology and the Handicapped.

For 36 years as a clinician, researcher, professor and administrator, I have devoted my professional life to serving handicapped persons both nationally and internationally. I am privileged in having been the first Director of the National Institute on Handicapped Research as well as having been elected a member of the Institute of Medicine of the National Academy of Sciences.

I would like to commend the Office of Technology Assessment for the outstanding report which has been a result of an arduous effort in offering both creativity and innovation for real betterment in the quality of life for the Nation's estimated 30 to 45 million handicapped persons.

The report combines the goals, objectives, and many concerns of research experts, consumers, rehabilitation agencies, and government agencies to explore and apply the vast potential of science and technology to the complex problems of the disabled community.

My remarks will focus on the issues which I feel we can realistically respond to regarding improved quality of life for the handicapped.

We must come to grips with the development and distribution of technological processes. Our ability to complete the circle starting with conception of technologies through research, development, evaluation, manufacturing, and marketing has not always resulted in the optimal delivery of this technology for use by handicapped persons. I will not attempt to elaborate on all these points, but rather concentrate my remarks on some major problem areas. We welcome the report's identification of problems and presentation of options for possible solutions.

Historically, the Veterans Administration has had a commitment to the disabled and has been an outstanding leader in contributing to the care of the disabled. We take pride in the truly-significant accomplishments in improvement in clinical service delivery and in the measurable successes of research and development efforts especially in prosthetics, spinal cord injury and sensory aids.

The Administrator of Veterans Affairs, Mr. Robert P. Nimmo, and the Chief Medical Director, Donald L. Custis, M.D., have consistently emphasized rehabilitation research and clinical care as a very high Agency priority. The Veterans Administration operates the Nation's largest health care delivery system consisting of 172 medical centers and 226 outpatient clinics. The VA's rehabilitation services are the focus of these facilities' efforts in rehabilitation. These services include Prosthetics and Sensory Aids Service, Audiology and Speech Pathology Service, Blind Rehabilitation Service, Rehabilitation Medicine Service, and Spinal Cord Injury Service. They provide the full range of programs necessary to prepare disabled veterans for optimal physical, psychosocial, and vocational adaptability upon their return to the community.

As providers dealing directly with disabled patients, the clinical and scientific staff members at VA medical centers are uniquely qualified to conduct research into the various existing problems of rehabilitation.

The report correctly identified marketing and diffusion of disability-related technology as a major concern of all researchers in this area. The VA Rehabilitation R&D Program has recognized this problem and has initiated an interagency agreement with the Minority Business Development Agency in the Department of Commerce. This project seeks to improve the ways to disseminate R&D accomplishments and encourages the involvement of small business manufacturers in the production and marketing of devices for the disabled. The VA is committed to providing quality service to handicapped veterans by making available the latest and most improved aids.

The option (from the report) presented for Congress "to amend current legislation to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies" and the options for Congress "to charter a private organization or establish a joint, public-private corporation to provide marketing and production related services to both the private and the public sectors" offer some exciting possibilities for involving the private sector in producing and marketing technical aids for the handicapped. The proposed changes in regulatory areas are interesting, but in my view do not appear to be as promising for long-term results. The overall effect of implementing such an option could provide a dramatic effect on the level of technology available to the handicapped.

A large gap exists between the researcher, the manufacturer, and the consumer. The transition of research prototypes into a reasonable realm of scale production is probably the most difficult hurdle to overcome. Possible inducements to industry to help close this gap could include tax incentives, cost-avoidance of equipment maintenance, development of manufacturer distribution, and reduction of the high cost of liability insurances. There should also be major steps taken to inform and convince industries of the possible lucrative "spill-overs" from the technology for the disabled. Provisions could be made to subsidize equipment for the manufacturer so that devices can be available to handicapped individuals without imposing severe financial burdens.

A concerted effort must also be made to encourage the early entry of industry in projects of research and development so that production and manufacturing may occur in a shorter time. Development, on the other hand, in many ways is more complicated than research because of its many facets. A major effort must be made to identify the devices, techniques, and concepts, which are ready or almost at the stage of readiness for utilization. Emphasis on this technology would accelerate the advance stage of research which could be beneficial to the disabled person. While accomplishing the above, we must still achieve the development of simple, inexpensive devices.

We must help the consumer get information on the available technology, where he can obtain it, and who will pay for it. More emphasis on printed and audiovisual media, telecommunications, workshops and conferences would be beneficial. We must also keep the consumer involved in long- and short-range planning. Dissemination of information is probably one of the most important parts of the loop in getting technology to the consumer. It is essential to keep the information on research and utilization complete, current in the "state-of-the-art", and indexed as to what is readily available. Marketing analysis with the consumer should be an ongoing process.

Application of technology for the disabled as a joint public charter with private venture might be useful. If a nonprofit organization such as the one described in Canada were established to function effectively, it would fill a definite need for marketing, supply and maintenance services, especially for devices which are not widely used. This option could provide a starting point for a cooperative program that might lead to wider use of federally-funded R&D. While this type of charter seems to be most often used by industrial institutions, it is not clear that this approach would be preferred for a widely-diverse program of technology transfer.

As a direct health care provider, the VA is keenly sensitive and supportive of consumer involvement. VA clinical researchers are involved in direct patient care and are sensitive to the needs of disabled persons. The VA Rehabilitation R&D Scientific Review Board has among its members disabled veteran representatives from six veteran service organizations. Veteran service organizations have traditionally been among the better organized groups supporting research and care of the handicapped. It would be unfair to the disabled community at large to be anything but supportive of efforts to obtain greater consumer involvement.

The three options regarding consumer involvement presented in the report, including the one mandating formal consumer involvement in all Federal or Federally-funded programs related to the development and use of disability-related technologies are approaches worth evaluating since they provide direct involvement of the disabled in the management process that is related so directly to their lives.

Personnel Issues

The VA, with its large, complex health care delivery system affiliated with all American medical colleges, is in a unique position, given necessary resources, to be able to implement programs such as those suggested regarding training of scarce category personnel. In the area of rehabilitation, for example, the VA Rehabilitation R&D program presently supports graduate rehabilitation engineering research personnel.

Reallocation of existing funds for training to increase numbers of disability-related personnel, including rehabilitation engineers, rehabilitation medicine physician specialists, and allied health professionals, is needed. Funding for training is an important commitment to the future for continued progress in improving the quality of life for handicapped individuals. These funds could have a significant impact on the number and quality of people entering the rehabilitation field. Education costs are at record levels, particularly at medical colleges, diverting part of the existing funds to support rehabilitation careers would attract more people to this field.

Demonstration projects to test reimbursement for technologies under Federal health insurance programs by the types of skills provided rather than by the types of providers present an important concept in rehabilitation. At present there are several groups that offer such services, but these are limited by the reimbursement criteria for service providers.

Each of the 3 options, addressed under personnel issues, has merit because each supports a different area. While any one of these options would beneficial, the combination of all 3 options would have a multiplier effect greater than the sum of the parts.

The influence of technology is felt in nearly every dimension of the lives of disabled people. As of August 1982, of the 30 million veterans, 3,100,000 were disabled (receiving compensation and pension benefits from VA). The overall problem in getting technology to the consumer is due to a set of complex issues which must be addressed.

Mr. Brown. Thank you very much, Dr. Giannini. We appreicate that.

Next, Dr. Colin McLaurin.

[The biographical sketch of Dr. McLaurin follows:]

BIOGRAPHICAL SKETCH OF DR. COLIN A. McLAURIN

Colin A. McLaurin, Sc.D. Engineering Director has over thirty years experience directing rehabilitation engineering research and development projects. At Sunnybrook Veterans Hospital in Toronto he developed the Canadian Hip Disarticulation Prosthesis which is used worldwide. At Northwestern University he was responsible for the devleopment of the hemi-pelvectomy prosthesis, a disc driction knee used extensively in Australia, the ring type harness for arm amputees and pioneer work on electrical prostheses for children. At the Ontario Crippled Children's Center in Toronto, the work on electrical prostheses continued, but the major contribution was the formation of a comprehensive research development and service program in rehabilitation engineering for children with physical disabilities. The program included a custom seating service and a variety of mobility aids including a modular powered wheelchair now being manufactured by Everest and Jennings, Canada.

At the University of Virginia, Dr. McLaurin has directed the engineering aspects of the Center, with a particular interest in the innovative design of wheelchairs. The "Stowaway" now going into service with United Airlines and others is one product from this design effort. During this period he has also served as President of the Rehabilitation Engineering Society of North America and is currently chairman of ANSI TC 173 SCI, the technical advisory group for wheelchair standards, representing the United States in the International Standards Organization (ISO).

Dr. McLaurin. I am a rehabilitation engineer at the University of Virginia. I have worked as an engineer in rehabilitation since 1949, about a third of a century. I have a fairly simple statement to make.

First of all, technology is wealth. Without technology, we would be a primitive people.

The bulk of technology, certainly a great part of it, is designed to overcome our own feeble muscles, our own feeble skills, and therefore I think it applies much more to disabled persons than it does able-bodied persons.

If we are going to advance technology in order to meet these needs, we have to have research and development. There is no secret to research and development. All it requires is a sustained commitment so you can get the right people on the job, let them assess the need, assess the technology, and go ahead and finish the job.

Assessing the need of course means contacting disabled persons themselves. We have many organizations such as United Cerebral Palsy, the Paralyzed Veterans of America, who have a good handle on this already. We recently received an excellent survey regarding the needs of wheelchair users from PVA.

With regard to assessing technologies we have had NASA, who has been a tremendous help in our work on wheelchairs in Virginia. You see some wheelchairs in this room. Two things wheelchair users want in a manual wheelchair is something light and durable.

Using what NASA has in the way of composite materials and also computer-aided design, it is not difficult to see how the weight of a wheelchair can be reduced by half and probably be more durable than it is now.

From the information NASA has on batteries, motors, and so on, it is not difficult to see how in the powered wheelchair, the range can be doubled. It is one of the things, perhaps the main thing, that troubles people about a powered wheelchair.

Now many things, and I think one of the earlier speakers referred to a device on wheelchairs to keep it from backing downhill, can reach people through cottage industries or can even be made by users themselves. However, most things in high tech, if they are to reach disabled people, have to reach them through industry. Fortunately we do have an active industry in this country and a good distribution system. The key then is how do you get this high tech into industry. That is where R&D comes in.

I happen to work in a university doing R&D on this. I am not sure a university is the best place, but I think it is, because we have access to scientists in medicine, scientists in engineering, and because it is a rehab setting, we have direct contact with the people who are going to use them. In any event, the thing I would like to emphasize is that it is really not the kind of academic research that we usually think of. The people in this particular center where I work find out what is available, and they design things to do the job, and we work with industry in getting them done.

I certainly commend what Dr. Reswick said about evaluation. That is something that also has to go along with research. The real thing I want to emphasize is that we do have in this country all the tools required to finish the job. We have access to the information, we do have the technology, and we do have delivery.

When NIHR was founded just a few years ago I think many of us felt that a whole new day was dawning. But slowly, year by year, dollar by inflation dollar, the door has been closing. If we want to do this job, it is simply a matter of holding the door open and letting the light of technology shine in on this very difficult problem.

Thank you.

[The prepared statement of Dr. McLaurin follows:]

TECHNOLOGY FOR THE HANDICAPPED

Research and Development - C. A. McLaurin

Technology as exemplified by the printing press, the heat engine, the cotton mills, the telephone, the aeroplane, the automated factory, space exploration and todays marvels of computer science, is the prime factor in determining our way of life compared to primitive man, the difference between wealth and poverty.

Research and development is the key to advancing technology, requiring both knowledge and expertise. The United States has a tremendous resource, a tremendous wealth of both knowledge and expertise, but surprising little has ever been applied to help the handicapped, even though this group of citizens stand to gain most from the application of technology, since in a large part, it has developed in order to expand and surplant our own feeble strength and skills.

There is no secret to research and development. It simply requires a sustained commitment to assess the need, to access existing knowledge, to employ the right people in the right place to solve the problem, and to evaluate the results.

The obvious way to assess the need, or rather needs since they are many varied, is to survey the disabled persons themselves. There exists many national organizations of, and for disabled persons such as United Cerebral Palsy, and Paralyzed Veterans of America who could serve in this capacity with or without federal funds.

We are fortunate to have the National Aeronautical and Space Administration as an enormous source of existing knowledge and expertise in technology. In my own area of interest, wheelchair mobility, they have, and continue to make in-valuable contributions in batteries, composite structural components, and in computer analysis for design. Further contributions are expected in electric motors, transmissions and controllers, all providing the latest in high tech which can be utilized by a small and diverse industry.

The key problem is getting this technology to industry. Although many devices can reach consumers via cottage industries or even home fabrication, it is reasonable to expect that only through the normal industrial and distribution processes can new products reach the majority of handicapped consumers. Fortunately, because some 17 Rehabilitation Engineering Centers have been in existance for several years through federal funding, there exists a number of engineers and related health care professionals who have knowledge and experience in developing technology for the disabled. What is needed is a long term commitment to fund such people in appropriate selected institutions with the specific purpose to develop new and improved products for and in cooperation with industry, utilizing NASA experience and knowledge in response to needs as they are defined.

A University may well be an ideal center for research and development because it does provide capable scientists in both engineering and medicine, but it should be noted that R & D is the application of science and should not be judged or funded as a typical scientific research project. The staff and facilities are needed to do a job and must be supported accordingly.

The development of new products is incomplete without evaluation and testing. In this regard, testimony of my friend and colleague, Dr. James Reswick is most applicable and must not be underestimated. It is the last but final step in securing responsible R & D for disabled persons. We have the tools, let us finish the job.

Mr. WALGREN. Thank you very much, Dr. McLaurin.

Would any of the Members like to raise any points with members of this panel?

Mr. BROWN. Could I ask just one question of Dr. Giannini.

It disturbs me of course to hear the last remark of Dr. McLaurin, which seems to imply a decrease in funds for research in this area. I wanted to ask you, Dr. Giannini, about the situation in the Veteran's Administration. I have long respected and admired the work being done there, and I wonder if you could comment on the degree to which it is being curtailed or increased at the present time. I should know that, but I do not, offhand.

Dr. GIANNINI. In 1982 we did have a reduction in funds, and we hope that after yesterday's session that that will be restored for 1983.

We have gone forward with our priorities and we have tried to be prudent in our selection of how we can best use our money, with a reduced budget, so that we could meet the most important unmet needs. In order to do that we had to telescope what our priorities would be, and that is what we have done. So in spite of our constraints I think that we have managed very well in going forward with what our goals and objective were.

Mr. BROWN. I think I understand the situation. Thank you.

Mr. WALGREN. If I could take the opportunity to ask Dr. Aller a question. Doctor, in your testimony you indicated that in 1983 the National Science Foundation is planning to reorient the program in this area. Could you elaborate on that? The question really is: Are programs for handicapped research going to have to compete against other engineering programs?

Dr. ALLER. You are talking about fiscal year 1983?

Mr. WALGREN. Yes.

Dr. ALLER. The budget presented to Congress as you know showed the change in management philosophy, and I have incorporated in my testimony the special remarks that Dr. Slaughter presented before your subcommittee during the authorization hearings. As I understand, the Congress has not yet reached a determination on what the NSF budget would be, and so if we go forward with our present proposal to you, as described by Dr. Slaughter, then there will be, of course, competition between those people who wish to do so-called applied research, motivated by helping the handicapped, with the regular research process, and that is intended to be sure that we support only the very finest research, whether or not it is motivated.

Mr. WALGREN. The intent I gather from Dr. Slaughter's remarks is to have programs related to physically handicapped compete directly for support with other proposals in engineering. On the one hand when you say the glass is half full, this broadens the possible base of support. On the other hand, if you look at it from the other possibility, it certainly lessens the actual effort in that area, without regard to whether that contribution to the handicapped is maintained or not.

It is our understanding that the language of the authorization indicated that that part of the program was to be continued. Is that your understanding also, Dr. Aller?

Dr. ALLER. It is my understanding that the House committee authorization contained such language, and that one of the two Senate authorization bills does. I have no idea where you are on this overall process, and it will depend on what is the final outcome, as to what will ensue. We have contingency planning to revert to the older management scheme, if that is the will of Congress. You have the proposal by our director for what he considers a superior way to manage this type of research, and I am a technical man.

Mr. WALGREN. Dr. Giannini, you indicated you had a reduction in funds. Looking back over the last let us say 5- to 10-year period, has there been an erosion in constant dollars, even though you may have had increases in funds. Has inflation undercut the actual, constant effort?

Dr. GIANNINI. As I can recollect—and the reason I am pausing is, I have been with the VA only a little over a year, but as I recall there had been a steady escalation of funds in small amounts, so that the erosion was not quite as devastating as it might have been. I think the cut, however, in 1982 was somewhat devastating, because it was more than we had anticipated.

Mr. WALGREN. Can you make an approximation of the percentage of the cut in constant effort?

Dr. GIANNINI. In 1982 we had a 23-percent cut in our budget.

Mr. WALGREN. And that would not account for inflation, although inflation is somewhat reduced. So you are suffering a greater than 23-percent loss, substantially greater.

Dr. GIANNINI. Yes.

Mr. WALGREN. Thank you very much. We certainly appreciate the contribution of the panel, and look forward to working with you and following up on your testimony. Mr. Dymally, will you take the chair?

Mr. DYMALLY [presiding]. Our next panel is one on consumer participation.

I would like to defer to Mr. Dunn from the State of Michigan to introduce Dr. Eulenberg and the gentleman accompanying Dr. Eulenberg.

Mr. DUNN. Thank you, Mr. Chairman.

Mr. Chairman, I would like to take this opportunity to introduce to the committee Dr. John Eulenberg. He is truly one of the world's foremost authorities on the development of mechanical language devices.

Dr. Eulenberg is a professor of linguistics, African language and computer science and is head of the artificial language laboratories of Michigan State University in East Lansing, Mich.

He has worked hard to develop a means by which men and women who are unable to talk can still communicate. The artificial language laboratory at Michigan State has attracted worldwide attention for its studies and innovation.

Dr. Eulenberg and staff have developed several unique devices to allow Americans who are unable to speak to communicate. One of the most advanced devices is the one used by Jim Renuk, who is attending this hearing with Dr. Eulenberg and will testify himself.

Jim is a graduate student of Michigan State who is afflicted by cerebral palsy. With the same spirit and determination that has made Jim a U.S. cerebral palsy swimming champion, he has worked with Dr. Eulenberg to develop and refine a device which allows Jim to communicate with a voice synthasizer.

Dr. Eulenberg will be discussing this process and other communication devices he and his staff have developed. The type of research and development being done at the artificial language laboratory serves as testimony to the need for education funding, particularly with respect to technological development.

In my home State of Michigan, the development of high technology will be an integral part of efforts to diversify the State's economy. I am sure everyone here will be fascinated and awed by the impressive devices that Dr. Eulenberg and Mr. Renuk are about to discuss.

As Americans, we should be proud of these individuals and everyone who is working to provide the ability to communicate for all people.

We all enjoy the constitutional right to freedom of speech, but we should not be satisfied until all Americans enjoy the freedom to speak. Dr. Eulenberg?

[The biographical sketch of Mr. Eulenberg follows:]

JOHN BRYSON EULENBERG, PH. D.

Dr. John Bryson Eulenberg is Associate Professor of Computer Science, Linguistics and African Studies at Michigan State University and Director of the MSU Artificial Language Laboratory. He received his B. Sc. at Massachusetts Institute of Technology, where he studied computer science, electrical engineering and German literature. He took his M.A. in linguistics at Harvard, where he was a teaching fellow in computational linguistics. His interest in African languages led him to the University of California, where he did dissertation research on the Hausa language of Nigeria, earning his Ph. D. degree from UC San Diego. Between 1961 and 1968, he worked summers at Zenith Radio Corporation in Chicago as an electrical engineer on infrared imaging devices and biosensory electronics. Between 1965 and 1972, he was a registered representative at two securities investment companies. From 1963 to 1972, he was president of Brysonian Films, a cinema production company in Massachusetts and California.

Dr. Eulenberg taught theoretical linguistics and African languages at Stanford University from 1969 to 1972, when he came to Michigan State University with a visiting appointment in Linguistics and African Studies. He joined the computer science faculty with a permanent appointment in 1974. At MSU he teaches courses in African languages and linguistics, linguistic theory, computational linguistics and computer science.

His Artificial Language Laboratory specializes in developing and exploring new technologies for human communication. Dr. Eulenberg is co-founder and publisher of Communication Outlook, the only national or international periodical focusing on the applications of technology for persons who experience severe communication handicaps. Dr. Eulenberg is co-developer of two computer-based interactive cable television systems, and is active in research on commercial and educational applications of broadband telecommunication networks.

Dr. Eulenberg and his wife Marcia live in East Lansing, Michigan with their children, Alexander and Rachel.

STATEMENTS OF MARGARET PFROMMER, PRESIDENT OF THE ILLINOIS COUNCIL, CONGRESS OF ORGANIZATIONS OF THE PHYSICALLY HANDICAPPED, AND RESEARCH ASSOCIATE, NORTHWESTERN UNIVERSITY REHABILITATION ENGINEERING PROGRAM, CHICAGO, ILL.; LATHAM BREUNIG, MEMBER OF THE BOARD OF DIRECTORS, ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF, ARLINGTON, VA.; JOHN EULENBERG, DIRECTOR, ARTIFICIAL LANGUAGE LABORATORY, MICHIGAN STATE UNIVERSITY, EAST LANSING, MICH., ACCOMPANIED BY JAMES RENUK, TECHNICAL ASSISTANT; AND ORAL MILLER, NATIONAL REPRESENTATIVE FOR THE AMERICAN COUNCIL OF THE BLIND, WASHINGTON, D.C.

Dr. EULENBERG. Thank you very much, Congressman Dunn and Mr. Dymally.

In the last 2 years, a new term has gained currency in the world of rehabilitation. This term is "VOCA," for voice output communication aid. A VOCA is a speech prosthesis: a talking computer designed to enable a nonspeaking person to express himself or herself in understandable speech.

The term "VOCA" was coined in the course of a project sponsored by the National Science Foundation which was carried out by Telesensory Systems, Inc., of Palo Alto, Calif., from whose president we will hear testimony today; and by the Center for Independent Living in Berkeley, Calif., from whom this committee is also hearing testimony. The project was directed at studying design factors in voice output communication aids. It had the participation of manufacturers, university-based research centers, and individual scientists throughout the United States. Although I appreciate the kind remarks of Congressman Dunn concerning our work at Michigan State University, I wish to stress that what we are seeing today is a team effort that extends all over our country and, indeed, throughout the world.

With funding from the National Institute of Handicapped Research, Michigan State University, through our University Center for International Rehabilitation, is privileged to participate as the national coordinating body in the United States for a four-nation project, the International Project on Communication Aids for the Speech-impaired [IPCAS]. We have joined Sweden, Canada, and the United Kingdom in a cooperative effort to help share the fruits of this technology on a worldwide basis.

As a research associate on the VOCA project, I think the highlight for me was a conference that was held at the University of California, Berkeley, in May 1980. It brought together not only researchers, but also VOCA users, persons who use talking computers to express themselves in spoken language.

They came from all over the country. Most of them used one of the two models of the Phonic Mirror HandiVoice [TM], which was the only commercially available speech prosthesis with unlimited vocabulary, but there were a number of research prototype systems represented, too. One attendee spoke by spelling out his words with his toe on a Texas Instruments speak and spell learning aid. It was an incredible experience, a moving experience for us all. We knew that the world had entered a new era in human communication.

We find, this year, commercially available and customized VOCA's costing thousands of dollars. People who need a voice cannot always afford one. But we have also witnessed this year the introduction of a new device by Texas Instruments, the VOCAID, for $150, based on learning aid and toy technology, but now being extended to meet the needs of human beings who need to communicate in an alternate way.

It is with great pleasure that I now introduce my colleague, Jim Renuk. Many of the people in this room have seen him and listened to his talks as he has traveled around the country. We have all applauded him as he won gold and silver medals in Denmark representing the United States in the cerebral palsy games.

I would also point out that this is the first time in history, to my knowledge, that anyone has used a talking computer to give testimony before Congress. This is a historic moment. I look forward to hearing about this happening often in Congress in the future.

I look forward to the day when the 1 million nonspeaking Americans who need to communicate and have a political voice will find that voice.

Thank you.

Mr. DYMALLY. We welcome you to the joint committee hearing and we ask you to proceed.

[The biographical sketch of Mr. Renuk follows:]

JAMES M. RENUK

James Renuk is a 29 year old graduate student at Michigan State University studying human nutrition. He received his B.S. in food science from MSU in 1979.

Mr. Renuk has worked for the Artificial Language Laboratory at Michigan State University since 1975 as a test pilot for voice-output communication aids. These aids were a part of several communication enhancement projects based in school districts throughout the state of Michigan. Mr. Renuk was the first person to give a speech using a talking computer, in the spring of 1977, and he gave the first speech using a wheelchair-portable talking computer in September 1978. Since then, he has traveled extensively throughout the United States and Canada demonstrating the state-of-the-art in voice output communication aids. He appeared on the documentary "Finding a Voice" in the Public Broadcasting System's 1982 NOVA series.

Mr. Renuk is an accomplished photographer and swimmer. He holds the U.S. gold medal in the Cerebral Palsy Games for swimming, and represented the U.S. Cerebral Palsy Team in international competition in July 1982 in Denmark, Copenhagen. There he won a gold medal in soccer and a silver in swimming.

Mr. Renuk's microcomputer-based communication system was developed at MSU's Artificial Language Laboratory. Mr. Renuk controls his system through a specially constructed hand-operated command lever with which he can select phonemes, words and prestored phrases and string them together for spoken and/or printed output. On the arm of his chair is a 20-character display window which allows him to monitor the position of his hand on the lever and to dynamically display the information he is preparing. Also on the arm of his chair is a small printer which allows him to take notes or leave messages. Mr. Renuk's system incorporates an output port which enables him to enter data into any standard computer terminal, using his command lever in place of a conventional keyboard. Mounted on the back of his chair is a small module containing the microcomputer, voice synthesizer, speaker, and all other electronic circuitry.

Mr. Renuk's system incorporates a Rockwell Aim 65 microcomputer and a voice synthesizer manufactured by Votrax Division, Federal Screw Works Company. Partial support for this work was provided by Votrax Division, Federal Screw Works Company and HC Electronics, Inc. which is hereby gratefully acknowledged.

The development of Mr. Renuk's system was sponsored by the Michigan Rehabilitation Services, Michigan Department of Education.

Mr. **Renuk**. Thank you.

I'm here today to talk about some of the problems that a communication handicapper has to face in life. A communication handicapper is a person who cannot speak or write efficiently. If a person is born a communication handicapper, he or she has to struggle to survive.

One of our major problems is in trying to get a good education. Our problems start when we are children. The teachers and other professionals most of the time misunderstand the communication handicapper child. This misunderstanding often leads these people to assume the child is much less intelligent. The price of this assumption is the loss of human mind power. With a little luck and a lot of very hard work, the communication handicapper may become highly educated.

Another problem is getting this highly educated person a well-paying job which would make him a taxpayer. If you take a look around, you will clearly see the discriminatory acts being carried out on communication handicappers.

Now, I want to talk about the majority of communication handicappers. These people are far less fortunate than I. I'm talking about the communication handicappers who are mistaken for severely mentally impaired and get put into State homes where they are sometimes subjected to physical abuse. These humans are also victims of an uglier form of abuse: psychological abuse. This kind of abuse is terrible because it has no telltale signs.

Just because people cannot communicate, why should they have to suffer like this? It saddens me to think of the trillions of dollars this country spends on war machines which can only destroy humankind. Today, we have the knowledge to give every American the right our forefathers dreamed of: free speech.

Mr. **Dymally**. We thank you very much for your testimony. I am quite sure the chairman would want to make a comment on this very outstanding display of computer technology here.

Mr. **Walgren** [presiding]. A fabulous demonstration. Can you tell us more about how it works?

Dr. **Eulenberg**. I think perhaps you could take up the American Association for the Advancement of Science on their invitation to the workshops in the next 2 days to get a more detailed explanation.

Jim is moving around with a joystick language space, as you would in three-dimensional space with the wheelchair machine. This is a research prototype funded by the Michigan Rehabilitation Services, a part of our department of education. This work was also supported by some of the technologists in this room as a joint effort.

Mr. **Dymally** [presiding]. Thank you very much, Dr. Eulenberg.

Mr. **Renuk**. Thank you.

Mr. **Dymally**. We will now hear from our next panelist, Margaret Pfrommer.

[The biographical sketch of Margaret Pfrommer follows:]

BIOGRAPHICAL SKETCH

Margaret Pfrommer is a Research Associate and Consumer Advocate with the Rehabilitation Engineering Program at Northwestern University, Chicago, Illinois. Ms. Pfrommer is President of the Illinois Council of the Congress of Organizations of the Physically Handicapped, and was director of the Illinois delegation to the White House Conference on Handicapped Individuals. Despite severe quadriplegia, through polio, she serves on a host of boards including the Consumer Advisory Council of the Illinois Department of Rehabilitation Services and the Advisory Committee to Research and Training Center #2. She is Chairman of the Board of Directors of Access Living of Metropolitan Chicago. She is widely recognized because of many media appearances in support of disabled persons.

The recipient of numerous awards, she has among these the Everest and Jennings Lectureship this year and recognition as a CMBES Fellow (Canadian Medical and Biological Engineering Society). Ms. Pfrommer was voted the Everest and Jennings award by the Board of Directors of the Rehabilitation Engineering Society of North America for her "enthusiasm and leadership" in behalf of rehabilitation engineering, particularly for her support of the role of th[illegible]umer of rehabilitation engineering products. In addition to presenting the main luncheon lecture at the Fourth Annual Rehabilitation Engineering Conference, Ms Pfrommer served as Co-chairman of the Program Committee and was especially active in providing consumer respondents for the many scientific sessions of the conference.

Ms. Pfrommer, a quadriplegic for the past twenty-five years, has benefited greatly from modern technical devices produced by rehabilitation engineering. With the aid of a puff-and-sip wheelchair and a home environmental system she lives independently in her own apartment. With the aid of a lift-equipped van and a driver, she commutes daily to a full-time job at Northwestern University. There she operates a computer-based system which enables her to complete, by puffing and sipping on a plastic straw, all the functions of a push-button call-directory phone. She can build and edit text on a monitor screen and put it in storage where it can be retrieved later for viewing. She also types out information for a printed copy. As a third set of functions, her system enables her to operate various appliances such as a tape recorder, room light, and slide projector.

Ms. Pfrommer believes that rehabilitation engineering is doing a good job, but that the consumer needs better service delivery, increased application and modification of appliances, and a wider dissemination of knowledge as to the technical devices that are available. Besides being disabled herself, Ms. Pfrommer's strong empathy with the consumer population derives from her many responsibilities and accountability to constituencies of other persons with disabilities.

Ms. **Pfrommer**. First of all, I would like to say through my association with the field of rehabilitation, I have been accepted by some as a professional. However, first and foremost, I am a person with a disability, a user of products and services, and I am an advocate, formally and informally, of all other persons with disabilities.

I see my fellow disabled receiving benefit from technical products and services, but not always maximum benefit, and not in large enough numbers. In my opinion, a major breakdown comes in service delivery: Inadequate numbers of trained and experienced clinical engineers and other professionals to properly apply and modify the existing technical aids and services, expense to the consumer who needs sensible and sensitive mechanisms of payment, inadequate sharing of information and expertise among rehabilitation professionals and other service agencies and departments, and lack of awareness or interest in the market on the part of manufacturers and distributors.

There is inadequate use of qualified consumers in every phase of the process from planning to testing to marketing. There is also inadequate use of qualified consumers on a national level. The OTA report, "Technology and Handicapped People," stresses the increased and better use of consumers.

I was originally requested, as part of my testimony today, to comment on the OTA report. I have submitted written comments in greater depth than present time permits. I request that these be included as part of my testimony. However, I must mention several OTA statements to which I take strong exception.

First, I, as a consumer, object to the whole idea of "defined goals" in evaluating the appropriateness of a technology. Many persons who assume the responsibility of defining goals do a better job of setting limitations, under the guise of being realistic.

For example, some professionals have refused to prescribe a pneumatic wheelchair control—puff-and-sip—for persons on ventilators because the professionals lacked the knowledge that such persons can make good use of this mode of operation. This is only one sample of what goes on in the field.

There are other situations in which a goal cannot be set before the consumer gets a chance to try a possible solution to his problem. Professionals who straitjacket themselves in "explicitly defining goals" deprive themselves, their clients, and the world of the ultimate benefits of technology.

Second, the OTA report stated flatly that R&D organizations have typically placed a low priority on production, marketing, and diffusion activities. It would be more accurate to say that, because of their limited resources, R&D organizations have been forced to place a low priority on the aforementioned activities.

Also, because R&D organizations are not mandated to engage in such activities, any efforts in this area are discounted when grants are being awarded.

Third, if the OTA report is to be used as a basis for developing policies regarding technology for people with disabilities, attention must be called to a contradiction which seems to pervade the entire document.

The very constraints identified as a cause of many of the obstacles to so-called appropriate technology are at the same time treated as inviolable in arriving at this "appropriate technology."

For instance, the OTA report notes that those who prescribe technologies may not be the best persons to do so, yet they are the ones whose values and goals are to be respected in arriving at "appropriate technology." Thus, we have a situation in which an identified cause of obstacles is set forth as a criterion for appropriate technology.

I cannot conceive of appropriate technology being developed or applied without the strong inclusion of consumers. In other words, a need must be established, and in order to establish that need, professionals working with technical products and services must have contact with the population of persons with disabilities.

Ongoing feedback from the consumer can keep all activities on track and prevent waste. Better products and services are obtained when they are evaluated by consumers under their own life circumstances and on their own terrain.

The consumer using a beneficial technical product or service develops a commitment to its promulgation that goes far beyond that of the typical professional 9-to-5 attitude. I have in mind such a consumer who worked with an R&D program that is part of an organization of government. The consumer knew the reliability of a product and also some of the obstacles in the way of its expanded use. One of these was that the benefits were not documented, thus making reimbursement difficult.

The same consumer had an opportunity to work with a group, funded by another organization of government, with the responsibility of establishing priorities of research for the handicapped in this country. This consumer was able to bring attention to the need for documentation of the benefits of existing technical aids.

This same consumer brought the matter to the attention of an R&T center, which is also a part of an organization of government; this time focus was on the specific aid. The R&T center was able to apply for a grant to study the particular aid. The grant was received because this consumer had previously helped to establish such documentation studies as a priority issue. The resulting documentation put on record proof that the benefits of the technical aid were cost effective. This is an example of a consumer taking the initiative to coordinate activities among government organizations.

There tends to be lack of coordination among government organizations in bringing good products and services to persons with disabilities. This opinion is not mine alone, but one I have heard expressed by consumers and professionals alike.

I would like to see a greater number of qualified consumers working to solve this problem and other problems on a national level. Consumers working on this level need to be truly representative of the population they serve.

If you look very closely, many consumer representatives do not fit what I feel is a definition of a qualified consumer.

Such qualified consumers should be persons who, (1) have a disability; (2) possess social maturity; (3) use technical products and services; (4) participate in consumer organizations or demonstrate a good contact with the community of persons with disabilities; (5)

represent the point of view of a sizeable number of persons with varying disabilities, being aware of a variety of lifestyles and experiences; and, (6) possess a working knowledge of the area in which they are participating.

I think these are very simple criteria which are not followed or understood.

There is a consensus among all who are involved with technology and handicapped people that independence and employability are not only important human aims but sound economic goals. It is generally recognized that the good use of technical products and services permits persons with disabilities to earn their own living and/or reduce assistance.

However, no matter how well people are equipped with technical devices and with personal and intellectual capabilities, the disincentives within our society prevent them from reaching their full potential for independence and employability.

Such disincentives include inaccessibility to buildings, programs, and facilities; archaic social security and tax structures; and attitudes which impede role changes.

Might I say, too, that the community of persons with disabilities right now is afraid that the changes to the Rehabilitation Act, more specifically section 504 which represents their civil rights, will be tampered with and they will lose what they have gained to date.

I see, as a consumer who is sophisticated in the field of R&D and R&T, that such tampering could cast a great shadow on the caliber of technology in this country, which in turn will hold back the future progress for persons with disabilities.

Dealing with and resolving these many problems can be overwhelming if we permit them to be. Along with you, I am ready to commit myself to the task.

Thank you.

[The prepared statement of Ms. Pfrommer follows:]

TESTIMONY OF MARGARET C. PFROMMER, RESEARCH ASSOCIATE/CONSUMER ADVOCATE, NORTHWESTERN UNIVERSITY REHABILITATION ENGINEERING PROGRAM AND PRESIDENT, ILLINOIS CONGRESS OF ORGANIZATIONS OF THE PHYSICALLY HANDICAPPED

My name is Margaret C. Pfrommer, I am a Consumer Advocate and Research Associate with the Northwestern University Rehabilitation Engineering Program. I am President of the Illinois Congress of Organizations of the Physically Handicapped. Through my association with the field of rehabilitation, I have been accepted by some as a professional. However, first and foremost, I am a person with a disability, a user of products and services, and I am an advocate, formally and informally, of all other persons with disabilities.

I see my fellow disabled receiving benefit from technical products and services, but not always maximum benefit, and not in large enough numbers. In my opinion, a major breakdown comes in service-delivery: inadequate numbers of trained and experienced clinical engineers and other professionals to properly apply and modify the existing technical aids and services, expense to the consumer who needs sensible and sensitive mechanisms of payment, inadequate sharing of information and expertise among rehabilitation professionals and other service agencies and departments, and lack of awareness or interest in the market on the part of manufacturers and distributors.

There is inadequate use of qualified consumers on every phase of the process from planning to testing to marketing. There is also inadequate use of qualified consumers on a national level. The OTA report, "Technology and Handicapped People," stresses the increased and better use of consumers.

I was originally requested, as part of my testimony today, to comment on the OTA report. I have submitted written comments in greater depth than present time permits. However, I must mention several OTA statements to which I take strong exception.

First, I as a consumer, object to the whole idea of "defined goals" in evaluating the appropriateness of a technology. Many persons who assume the responsibility of defining goals do a better job of setting limitations, under the guise of being realistic. For example, some professionals have refused to prescribe a pneumatic wheelchair control (puff-and-sip) for persons on ventilators because the professionals lacked the knowledge that such persons can make good use of this mode of operation.

There are other situations in which a goal cannot be set before the consumer gets a change to try a possible solution to his problem. Professionals who straight-jacket themselves in "explicitly defining goals" deprive themselves, their clients, and the world of the ultimate benefits of technology.

Second, the OTA report stated flatly that R&D organizations have typically placed a low priority on production, marketing, and diffusion activities. It would be more accurate to say that, because of their limited resources R&D organizations have been forced to place a low priority on the aforementioned activities. Also, because R&D organizations are not mandated to engage in such activities, any efforts in this area are discounted when grants are being awarded.

Third, if the OTA report is to be used as a basis for developing policies regarding technology for people with disabilities, attention must be called to a contradiction which seems to pervade the entire document. The very constraints identified as a cause of many of the obstacles to so called "appropriate technology" are at the same time treated as inviolable in arriving at this "appropriate technology." For instance the OTA report notes that those who prescribe technologies may not be the best persons to do so, yet they are the ones whose values and goals are to be respected in arriving at "appropriate technology." Thus we have a situation in which an identified cause of obstacles is set forth as a criterion for appropriate technology.

I cannot conceive of appropriate technology being developed or applied without the strong inclusion of consumers. In other words, a need must be established, and in order to establish that need, professionals working with technical products and services must have contact with the population of persons with disabilities. On-going feedback from the consumer can keep all activities on track and prevent waste. Better products and services are obtained when they are evaluated by consumers under their own life circumstances and on their own terrain.

The consumer using a beneficial technical product or service develops a commitment to its promulgation that goes far beyond that of the typical professional nine-to-five attitude. I have in mind such a consumer who worked with an R&D program that is part of an organization of government. The consumer knew the reliability of a product and also some of the obstacles in the way of its expanded use. One of these was that the benefits were not documented, thus making reimbursement difficult.

The same consumer had an opportunity to work with a group, funded by another organization of government, with the responsibility of establishing priorities of research for the handicapped in this country. This consumer was able to bring attention to the need for documentation of the benefits of existing technical aids.

This same consumer brought the matter to the attention of an R&T center, which is also a part of an organization of government, this time focus was on the specific aid. The R&T center was able to apply for a grant to study the particular aid. The grant was received because this consumer had previously helped to establish such documentation studies as a priority issue. The resulting documentation put on record proof that the benefits of the technical aid were cost effective. This is an example of a consumer taking the initiative to coordinate activities among government organizations.

There tends to be lack of coordination among government organizations in bringing good products and services to persons with disabilities. This opinion is not mine alone but one I have heard expressed by consumers and professionals alike.

I would like to see a greater number of qualified consumers working to solve this problem and other problems on a national level. Consumers working on this level need to be truly representative of the population they serve. Such qualified consumers should be persons who (1) have a disability (2) posses social maturity (3) use technical products and services (4) participate in consumer organizations or demonstrate a good contact with the community of persons with disabilities (5) represent the point of view of a sizeable number of persons with varying disabilities, being aware of a variety of life-styles and experiences (6) possess a working knowledge of the area in which they are participating.

There is a consensus among all who are involved with technology and handicapped people that independence and employability are not only important human aims but sound economic goals. It is generally recognized that the good use of technical products and services permits persons with disabilities to earn their own living and/or reduce assistance.

However, no matter how well people are equipped with technical devices and with personal and intellectual capabilities, the disincentives within our society prevent them from reaching their full potential for independence and employability. Such disincentives include inaccessibility to buildings, programs, and facilities; archaic social security and tax structures, and attitudes which impede role changes.

Dealing with and resolving these many problems can be overwhelming if we permit them to be, but, along with you, I am ready to commit myself to the task.

COMMENTS BY MARGARET C. PFROMMER, CONSUMER ADVOCATE AND RESEARCH ASSOCIATE WITH NORTHWESTERN UNIVERSITY REHABILITATION ENGINEERING PROGRAM AND PRESIDENT OF THE ILLINOIS CONGRESS OF ORGANIZATIONS OF THE PHYSICALLY HANDICAPPED

I have spent many hours reviewing OTA's report entitled Technology and Handicapped People. I was pleased to find in it a recognition of problems which prevent optimum use of technology by persons with disabilities. However, I am dismayed to see that the very constraints identified as a cause of many of the problems are at the same time treated as inviolable.

For instance, the report notes that those providers who select technologies "may not be the most appropriate ones to do so." Yet these inappropriate ones are termed "parties at interest" whose "values and goals give meaning to the appropriate application of technology." I have had the good fortune of working with some professionals who are skillful in their applications. I also have had the misfortune of being client of other professionals whose incompetence contributed to my many years of unnecessary discomfort, dependence, and isolation.

The report acknowledges that "disabled people are denied funding for technologies that are clearly appropriate." At the same time "appropriate technology" is said to be "compatible with resource constraints." Thus we have a situation in which identified causes of obstacles are set forth as criteria for appropriate technology.

There are other statements with which I, as a person with servere disabilities, strongly disagree. I think it is inaccurate to state that "In some cases, technology is the cause of impairments, disabilities, and handicaps." I believe that the misuse or misapplication of technology causes disabilities. Underuse of technology can deprive an entire society.

I, as a consumer, object to the whole idea of "defined goals" in evaluating the appropriateness of a technology. Many persons who assume the responsibility of defining goals do a better job of setting limitations, under the guise of being realistic. For example, some professionals have refused to prescribe a pneumatic wheelchair control (puff-and-sip) for persons on ventilators because the professionals lacked the knowledge that such persons can make good use of this mode of operation.

It is not possible to explicitly state goals. What is possible, and often happens, is that the prescribed technology opens such opportunities, undreamed of by any of the "parties at interest", that a desire and need for additional technology is created. In my work with the application of technology I have often been amazed to see the positive synergistic effects when good application and use is made of one of more technical aids. Professionals who straight-jacket themselves in "explicitly defining goals" deprive themselves, their clients, and the world of the ultimate benefits of technology.

I would briefly like to call attention to important areas of concern that must be dealt with in order to bring necessary technology to potential users. I as a consumer have been promulgating recommendations for many years. They bear repeating.

(1) There must be a greater involvement of qualified consumers in the research and development, evaluation, and service delivery of technical products and services. There should be more activities for consumers written into applications for grants and more use made of consumers in reviewing proposals on a national level.

(2) Manufacturers and distributors need to be encouraged and supported in the production and marketing of technical aids. They in turn must assume responsibility for reliable products which can be adequately maintained.

(3) More flexible funding mechanisms have to be created to meet the varying needs of persons who have limited or no resources. There needs to be a reclassification of technical equipment as "non-medical" and not requiring a doctor's approval.

(4) There should be better dissemination of information about available technologies, their benefits, and new techniques in their application.

(5) We need more extension evaluations of technologies and development of methods of analysis. All information could be included in a comprehensive Consumers Report to insure better investments in the purchase of technical aids and services.

(6) There is a need for an increased number of well-trained persons to work in all areas of research and development, evaluation, application, and service-delivery of technology. Even more important is the need for upgrading the skills of professionals who presently have the responsibility of applying technology.

Following is my comment on the Policy Options in the OTA report.

PRODUCTION, MARKETING, AND DIFFUSION OF TECHNOLOGIES

Issue 1.—How can the Federal Government increase the probability that technologies will reach the people who need and desire them?

It is not quite fair to say flatly that "R&D organizations have typically placed a low priority on production, marketing, and diffusion activities." It would be more accurate to say that, because of their limited resources, R&D organizations have been forced to place a low priority on the above mentioned activities. Also, because R&D organizations are not mandated to engage in the production, marketing, and diffusion of technologies, any efforts in this area are discounted when grants are being awarded. Actually, the typical R&D organization, having put forth great effort in developing a product or service is eager to see it produce beneficial results to as many people as possible.

Option 1A, for "Congress to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies" seem to me to be difficult, perhaps impossible, and at least, time-consuming.

In addition to the problem of identifying and reviewing many statutes and regulations and of amending fiscal monetary, and regulatory policies—all of which are noted by OTA—there is another problem not mentioned. Universities have their own policies and practices which will at times inevitably come into conflict with the economic goals of private industry. Because R&D programs are specifically mandated to be operated under university auspices, this mandate could present further obstacles to any options. Such obstacles may not be insurmountable, but OTA needs to identify them and their impact on this area of concern.

Option 1B, for "Congress to legislatively charter a private organization to provide marketing and production-related services, sounds promising, especially if the evaluation projects can, as suggested, "be clearly and cleanly separated from the functions of assisting the marketing of products." I urge very strongly that a component of any evaluation process include a Consumers Report independent of the manufacturer. A good evaluation takes on three aspects: (1) testing of engineering performance (the technical specifications), (2) studying a product's applicability, reliability, serviceability, and maintenance system, (3) examining the subjective responses of the user and of professionals involved with its application.

I also feel very comfortable with the stipulation "that the proposed organization should have broad representation of many different groups and constituencies." What better way to bring about understanding among people of different disciplines and to safeguard the interests of the consumer. The "governmental grants and contracts referred to would have to be reviewed. If expectations were not being met, there would be no option for renewal.

Option 1C—Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and the public sector.

I find merit in Option C but would like to see such a public-private corporation not so much as one to promote transfer of products from R&D to private industry but as an organization structured to resolve present health-care issues by delivering services directly to consumers.

INVOLVEMENT OF DISABLED PEOPLE AND OTHER CONSUMERS

Issue 2.—How can policies and programs be designed to encourage or assure the effective involvement of disabled people and other consumers in the development and delivery of technologies? In addition to providing information, consumers should themselves be part of advisory and policymaking bodies to the maximum extent feasible.

Another obstacle not mentioned by OTA, in the way of eager consumer involvement is the patronizing attitude on the part of professionals toward the consumer. This is a principal reason why the consumers fail to "see themselves as having something to contribute." They are not encouraged to believe that the relationship is one of mutual benefit, which it is. The professional cannot have as high a degree of success without the good information and feedback provided by an actual user of their products and services.

I like the idea expressed in Option 2B of creating "an office of consumer involvement to conduct, monitor, and provide technical assistance regarding the involvement of disabled people." I would hope, however, that this office would be staffed with qualified consumers.

RESEARCH, DEVELOPMENT, AND EVALUATION OF TECHNOLOGIES

Issue 3.—How can R&D activities be organized and funded to produce knowledge techniques, or devices that service the needs of disabled people and relevant providers in accordance with the magnitude of various problem areas and opportunities? How can evaluation of present and ongoing technologies be organized to provide consumers, providers, and policymakers with adequate information?

Option 3C (Congress could appropriate specific increased funds for evaluation of technologies) is the best proposal for expanding the level and quality of current evaluations without the potential conflict of interests with the manufacturers that would occur under Options A and B. It creates a good opportunity for the development of methods of analysis and for identifying and soliciting appropriate consumers for the evaluation of technical aids and services. It would give an opportunity to share understandable information with persons involved both in R&D and marketing aspects. Information could automatically be funneled into a comprehensive Consumers Report to insure better investments in the purchase of technical aids and services.

FINANCIAL BARRIERS TO THE USE OF TECHNOLOGY

Issue 4.—How can financial barriers to the acquisition of technologies by disabled people be reduced within reasonable constraints? Can the levels and distribution of available funding be made more appropriate in relation to the level of the problem addressed?

Options A and B address the needs of two groups of people: those who have the capability to generate some funds and those who must rely on government health insurance programs. If the activities of the two options were coordinated, they would probably serve the largest number of persons with disabilities who need technology.

The oversight hearings of Option 4B should foster reimbursements for non-medical products and services and for those who deliver them. At the present time a common complaint of those delivering rehabilitation engineering services is that they constantly have to look for funding, which steals time and energy from their rightful area of expertise.

Another area of attention for oversight hearings is that of upgrading the reimbursement mechanism to provide more sophisticated technologies which can clearly be justified on the basis of cost effectiveness and/or improved quality of life.

A mechanism should be developed for the repair of technical aids. Because of a person's heavy dependence on a particular aid, provision should be made for duplicate purchase or for a "loaner" during periods when repairs are being made. Because of the recent cut or elimination of green card benefits, people who own equipment are unable to purchase replacement parts or make repairs. This renders their equipment useless and erodes their independence and productivity.

Because denials for "nonmedical" technologies "usually occur at the state or regional level," I am fearful of more power being turned over to state agencies which do not efficiently and effectively use funds for their intended purpose.

PERSONNEL ISSUES

Issue 5.—How can Federal policies assure an adequate number of well-trained personnel at all stages of the development and use of technologies? Systems for R&D as well as delivery of services should provide incentives for the cost-effective use of these personnel.

I find something of value in all of the options. I am in favor of training persons with disabilities to become professionals referred to in Option A. However, to guarantee the consumer viewpoint, some consideration should be given to the establishment of formal positions for qualified persons with disabilities, enabling them to work in existing R&D, evaluation, and service delivery programs. Sometimes professional training can interfere with a disabled person's being a typical consumer. Professionals (disabled or not) operate within their discipline, think within it, strive for objectivity. Disabled persons equipped principally with their own life experiences can and do bring a certain naivete, an openness, as well as a subjectivity, a questioning, that can prove illuminating. I would like to see more situations where qualified consumers work side by side with trained personnel in R&D, evaluation, and service programs, each with respect for the other and for what the other can bring.

Reimbursement for the expenses of volunteers, as recommended in Option B, needs to be made more flexible and commensurate with varying expenditures. For example, twenty cents a mile would not compensate a volunteer with a disability, nor would a tax break be applicable to the situation of a person who is on some government maintenance program.

In regard to Option C which suggests the establishment of demonstration projects, OTA states that "those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so."

Persons in the rehabilitation engineering professions are concerned at the present time with such questions as: Are individuals or groups of individuals (facilities) "appropriate" providers of services? Who is appropriate and how can they be certified? What would be the criteria for such certification? Could a person be certified in a particularly specified area (e.g. wheelchairs) and be eligible for direct reimbursement? How can the status of rehabilitation engineering products and services be changed from "medical" to "non-medical," and should this change be made? How can the system of reimbursement be changed to cover the provision of rehabilitation engineering products and services by non-medical personnel?

To effect proper technical solutions. The demonstration projects could provide an abundance of information, some of which might be helpful in determining the need for certification for persons providing services and in establishing what criteria should be used for certifying an individual or a team.

Mr. DYMALLY. Thank you very much.

Now, we will hear from Dr. Breunig.

[The biographical sketch of Dr. Breunig follows:]

VITA

H. Latham Breunig, Ph.D.

7108 27th Road North; Arlington, Virginia 22213; 301-588-4605(Voice/TTY relay)
703-534-3414(TTY only)

Born: November 19, 1910; Indianapolis, Indiana
Hearing Loss: 25% age 3, unknown; 60% age 5, scarlet fever; 95% age 7, skull fracture

Education: Clarke School for the Deaf; Northampton, Mass.; 1920-1927
Shortridge High School, Indianapolis, IN; 1927-1930
Wabash College, Crawfordsville, IN; AB (Chem) 1934
Johns Hopkins University, Baltimore, MD; Ph.D. (Chem) 1938
Purdue University, West Lafayette, IN; 1956-57; Statistics and Quality Control

Employment: Eli Lilly and Company, Indianapolis, Indiana

Laboratory Assistant	1931-1938 (summer employment)
Chemist	1938-1956
Statistician	1956-1965
Senior Statistician	1965-1975

Activities and Organizations
- Attended International Symposium on Quality Control of Drugs, Buenos Aires (1970)
- American Society for Quality Control; Quality Engineer (1966), Fellow (1969)
  - President, Chemical Division (1967-68)
- American Statistical Association
  - President, Central Indiana Chapter (1963-64)
- Pharmaceutical Manufacturers Association
  - Chairman, Standing Committee on Statistics (1972-74)
- Eagle Scout (1927); International Jamboree (1929)
- Clarke School for the Deaf, Northampton, MA
  - Board of Trustees (1946-); Vice Chairman
- Alexander Graham Bell Association for the Deaf, Inc. (1956-)
  - Board of Directors (1960-1982)
  - President (1976-78)
  - Chairman of Governmental Relations Committee, (1982-)
- Telecommunications for the Deaf, Inc. (TDI)
  - Founder and Chief Executive Officer (1968-1978)
- Smithsonian Institution; Advisory Committee on Special Education (1979-)
- Falls Church Presbyterian Church; Deacon (1979-1982)
- National Council on the Handicapped, Nominee (1982)
- President's Committee on Employment of the Handicapped
- International Symposium on Education of the Deaf, Leipzig, East Germany (1978)

Special Awards (Partial List)
- President's Committee on the Handicapped, Commendation, Lyndon B. Johnson (1967)
- Sertoma International, Midwest Region; Service to Mankind (1968)
- Sagamore of the Wabash (Governor Branigin of Indiana) (1969)
- Telephone Pioneers of America, Honorary Member, (1973)
- Teletypewriters for the Deaf, Inc. (TDI); H. Latham Breunig Award - first recipient (1977)

Also numerous publications and papers in the fields of statistics, quality control, deaf education and telecommunications

Married 1938 to Nancy D. Tyree of Lynchburg, VA; three children, seven grandchildren

September 27, 1982

Dr. BREUNIG. Thank you very much, Mr. Dymally. Can you hear me all right?

Mr. DYMALLY. Very well, sir.

Dr. BREUNIG. My name is H. Latham Breunig, Ph. D. I am past president of the Alexander Graham Bell Association for the Deaf, Inc., and I have been nominated by the President to the National Council on the Handicapped. The Senate Committee on Labor and Human Resources and the House Subcommittee on Science, Research, and Technology are to be commended for the intiative that has led to the investigations by the Health and Sciences Division of the Office of Technology Assessement into the broad area of technology and handicapped people.

The OTA project staff, "Technology and Handicapped People," is to be complimented on this very thorough research, which will undoubtedly have far-reaching implications in many areas of the public and private sectors dealing with disabled persons. Their policy options reflect considerable insight on their part.

I would have liked to have had more time available to me than the month between the arrival of the invitation to testify, together with the full report, and my appearance here today in order to comment more indepth on this very comprehensive report. Even more helpful would have been an ongoing awareness that the investigation was in progress.

Although I have been given the specific charge of commenting on consumer interests, I would first like to make some general observations.

TERMINOLOGY

I am very pleased with the distinction the report makes among "impaired," "disability" and "handicapped." I have no quarrel with the definition of impairment given on page 192 of the report.

With the word, "disability," however, I have a problem of semantics. The definition in the glossary, page 191, reads, "A term used to denote the presence of one or more functional limitations." Limitations on what? On human activities?

A person with a disability has a limited ability to perform one or more basic life functions; for example, walking, at a level considered "typical."

With hearing loss, how does one "perform" hearing? Perhaps "carry on" or some other alternative would be more descriptive.

"Handicap" is described as the "inability to perform one or more life functions"; for example, eating, conversing, working, at a "typical" level, caused by the interaction of the individual's disability with the physical and social environments in which the person is functioning or is expected to function.

In the Volta Review[1] reference is an article entitled "Latham Bruenig: A Deaf Boy Without a Handicap." Ever since the time this article appeared, I have weighed the implications of the word "handicapped" and have resisted its application to me.

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[1] See attachment.

I must admit, however, that it is sometimes useful; for example, for getting special license plates or parking in restricted places. Let us consider the source and use of the term.

Although I have lost the reference, I read years ago that the word "handicap" dates from early times when knights and dukes, who depended upon horses for transportation, often debated the merits of their respective steeds and set up competitive races.

Since the duke would usually be wealthier than the knight, he would be able to own a horse with a better bloodline and capability. To equalize the competition they needed to decide upon starting points for the horses in the race. They did this by putting stones of different shape or color into a hat, drawing from it and then—I am not sure just how—determining the initial placement of the horses.

Thus arose the term "hand-in-the-cap." Over the years, the term has come to mean advantages or disadvantages placed upon unequal competitors in order to equalize their performance.

Thus we have weights in the saddles of race horses, and handicap strokes given golfers. If, then, a handicap is a weight placed upon competitors to equalize their opportunities, it would appear that the good Lord, in his infinite wisdom, has placed "handicaps" on those of us who are disabled because it could be that we are inherently superior to our fellows who are "able."

At one time I had a reference, which I have been unable to locate, to the effect that "handicap" was to be considered a psychological aspect of a person's makeup. Whether one with a disability is handicapped must be related to a realistic assessment of one's abilities and opportunities in "physical and social environments."

Such a realistic assessment by the disabled individual himself is the key to "success," although others may provide stimulus and encouragement. Should I aspire to play a violin at the concert level, I would be "handicapped" by my "disability;" for example, hearing loss.

But I do not realistically so aspire, so I am not "handicapped" in that regard. I therefore reject the blanket term "inability to perform" which is repeated from the definition of "disability."

I would substitute "an impaired capacity to carry on various life activities caused by interaction with physical, social, or psychological environments in which that person realistically desires or is expected to function." Who is to say whether or not a functional task is "typical"?

The report properly recognizes that degrees of disability exist, that the greater the disability and its effect upon lifestyle become, the more handicapped an individual may become and that public and private intervention may be required for amelioration of the individual's circumstances.

On the other hand, literature is replete with success stories, some of which are pictured in the report, of individuals who have refused to allow their disabilities to handicap them.

I do not know where the word handicapped first appeared in reference to disabled persons, but I suspect it was used by insensitive able-bodied persons who looked at the negative instead of the positive aspects of life.

Although I know not all of my disabled friends will agree with me, I consider the word a put down, and at the same time frown upon those who would use the word to gain advantage for themselves.

It was something disappointing to see the word handicapped used in the title of this report, valuable though it otherwise may be. Although, in a practical sense, it may be unrealistic to retrofit all statutes, regulations, and reports by replacing handicap with disability, I am encouraged by the more frequent use of the latter in recent times, such as in the "International Year of the Disabled."

On page 21 of the report is reference to stigma being attached to the disabled. In my opinion, there is much more stigma attached to handicapped.

It was disappointing, also, to note, page 22, the use of the unfortunately widespread term "deaf and hearing impaired." This terminology is incorrect. Hearing impairment is a generic term which includes all degrees of hearing loss, that is, the categories of deaf and hard of hearing.

The correct terminology as used by the various professional associations concerned with hearing impairment—Alexander Graham Bell Association for the Deaf, American Speech-Language-Hearing Association, Council on Education of the Deaf, et cetera—is hearing impaired—deaf and hard of hearing.

Similarly, blind and vision impaired does not make much sense, although my friends in the field of vision impairment tell me that the term is currently acceptable to them.

STATISTICS AND DATA

As a professional statistician, though retired, I am appalled at the number of far-reaching decisions, at how much legislation is enacted on the basis of inadequate information, and at the fact that statistical compilations are apparently being targeted for budget cuts in many areas of the Federal Government.

The report properly addresses this area in stressing the need for information systems such as NCHS, NARI, and ABLEDATA working hand in hand with the Bureau of the Census. In this connection, it is interesting to note—Washington Post, September 23, 1982, Federal Report—that the administration has embarked upon a "Reform 88" management reform package which is purported to allow the Federal Government to operate as efficiently as a major corporation.

The program includes 33 senior managers from 13 agencies. I strongly urge that programs for the disabled be included in this effort, incorporating some of the options developed by the report, to which I will refer later on in this testimony.

CONSUMER INVOLVEMENT

The report repeatedly stresses in very specific ways the need for consumer involvement which is a continuation of trends evident over the past decade.

It would seem that such involvement is essential in all areas of identification, planning, research and development, evaluation and delivery. Given the considerable number of specific disabilities encountered, and the tendency for people in each consumer area to be protective of their "turf," the report urges that program and project manager systems which encompass comprehensive technology assessment be established.

This implies assessment by groups which include disabled people who are able to recognize the needs of other disabilities.

At a personal level, my current membership on a docent training manual team of the Department of Special Education for the Smithsonian Institution is giving me considerable insight into other areas, which include six major disability groups, for example, hearing impairments, visual impairments, mobility impairments, emotional impairments, learning disabilities, and developmental disabilities.

All of these areas are represented by at least one member of the team, usually a person with the specific disability. Bringing all of these diverse areas into one workable document is a challenging task. It is enlightening, to say the least, to sit through a 2-hour meeting in which three vision-impaired persons discuss the concerns of their disability and appropriate entries in the training manual.

The report has concluded that little of value has resulted from the money, time, and efforts of the myriad research centers and programs supported by the Federal Government, and points out that the tactical goal of consumer involvement is realism. Consumers and groups or organizations with which they interact should gain a more realistic appreciation of each other's needs and capabilities.

To accomplish a coordinated disability policy and program it would seem options 2A and 2B should be combined to afford continuing oversight. The report also sets up policy options 1, 3, 4, and 5, which, together with option 2, encompass a broad, comprehensive set of objectives.

With so many options before it, Congress needs guidance from a central source which is able to focus on broad, impartial overview of the entire disability field. It would seem that the one group which, by its very title, would be the logical group to do so, is the National Council on the Handicapped.

NCH is mandated to review all policies and activities concerning disabled persons conducted or assisted by a Federal agency.

It seems somewhat unfortunate that NCH has been relatively ineffective for several reasons, which include: One, its membership has been subjected to the winds of political change which have destroyed its continuity; and, two, its funding is relatively modest, leading to limitations in its staffing and in the ability of members to meet together.

By statute, NCH establishes policies for the National Institute for Handicapped Research, the lead agency in evaluation of technologies for disabled people. It reviews the policies of the Rehabilitation Services Administration, which is mainly State-oriented and funded.

To improve its effectiveness as a national council, NCH needs to be charged with more specific oversight of all other areas in the Federal Government which deal with disabilities. In order to accomplish this, NCH must be removed from the political process and given adequate funding.

It would appear desirable to establish, as outlined in options 1B and/or 1C, under NCH a joint public or private corporation to provide identification, demographics, planning, or appropriate technology, carrying out research and development, evaluation, marketing and diffusion, delivery, monitoring use, financing, and finally, resource development and allocation.

Such a chartered private, or public-private corporation would be eligible to receive Federal grants, and State and private funding. Its primary focus would be at the State level, as sought in the current political climate, providing uniformity of operations among the various States, but be overseen at the national level by NCH for consistency in policy.

As the report suggests, the Canadian Technical Aids and Systems for the Handicapped, Inc., should be looked into. On the other hand, the models of the National Captioning Institute and of the Communications Satellite Corp. might suggest more effective ways of dealing with the situation.

In any event, disabled consumers would comprise a substantial percentage of the management of such an enterprise. The corporation could be started by RFP from a strengthened NCH, which would be the ultimate authority.

In conclusion, I would urge that all areas of disability be brought together under the oversight of one body, such as NCH, which would have the ultimate composition, funding and authority from Congress to bring into uniform focus all efforts in the disability field.

[The prepared statement of Dr. Breunig follows:]

Testimony of

H. LATHAM BREUNIG, Ph.D.

to a joint meeting of the

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

and the

HOUSE SUBCOMMITTEE ON SCIENCE AND TECHNOLOGY

to review the Report of the Office of Technology Assessment entitled

TECHNOLOGY AND HANDICAPPED PEOPLE

September 29, 1982

The Senate Committee on Labor and Human Resources and the House Subcommittee on Science and Technology are to be commended for the initiative that has led to the investigations by the Health and Sciences Division of the Office of Technology Assessment into the broad area of technology and handicapped people. The OTA project staff--Technology and Handicapped People, is to be complimented on this very thorough research, which will undoubtedly have far-reaching implications in many areas of the public and private sectors dealing with disabled persons. Their Policy Options reflect considerable insight on their part.

I would have liked to have had more time available to me than the month between the arrival of the invitation to testify, together with the full report, and my appearance here today in order to comment more in depth on this very comprehensive report. Even more helpful would have been an ongoing awareness that the investigation was in progress.

Although I have been given the specific charge of commenting on consumer interests, I would first like to make some general observations.

Terminology

I am very pleased with the distinction the report makes among "impaired," "disability" and "handicapped." I have no quarrel with the definition of impairment given on page 192 of the Report. With the word "disability," however, I have a problem of semantics. The definition in the glossary (p. 191) reads, "A term used to denote the presence of one or more functional limitations. (Limitations on what? On human activities?) A person with a disability has a limited ability to perform one or more basic life functions (e.g., walking) at a level considered "typical." With hearing loss, how does one "perform" hearing? Perhaps "carry on" or some other alternative would be more descriptive. "Handicap" is described as the "inability to perform one or more life functions (e.g., eating, conversing, working) at a "typical" level, caused by the interaction of the individual's disability with the physical and social environments in which the person is functioning or is expected to function (p. 192).

In the Volta Review (32 (4) April, 1930, p. 161) is an article entitled "Latham Bruenig (sic): A Deaf Boy Without a Handicap." Ever since the time this article appeared, I have weighed the implications of the word "handicapped" and have resisted its application to me. (I must admit, however, that it is sometimes useful, e.g., for getting special license plates or parking in restricted places.) Let us consider the source and use of the term.

Although I have lost the reference, I read years ago that the word "handicap" dates from early times when knights and dukes, who depended upon horses for transportation, often debated the merits of their respective steeds and set up competitive races. Since the duke would usually be wealthier than the knight, he would be able to own a horse with a better bloodline and capability. To equalize the competition they needed to decide upon starting points for the horses in the race. They did this by putting stones of different shape or color into a hat, drawing from it and then (I am not sure just how) determining the initial placement of the horses. Thus arose the term "hand-in-the-cap." Over the years the term has come to mean advantages or disadvantages placed upon unequal competitors in order to equalize their performance. Thus we have weights in the saddles of race horses, and handicap strokes given golfers. If, then, a handicap is a weight placed upon competitors to equalize their opportunities, it would appear that the good Lord, in his infinite wisdom, has placed "handicaps" on those of us who are disabled because it could be that we are inherently superior to our fellows who are "able."

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It was somewhat disappointing to see the word "handicapped" used in the title of the report, valuable though it otherwise may be. Although, in a practical sense it may be unrealistic to "retrofit" all statutes, regulations, and reports by replacing "handicap" with "disability," I am encouraged by the more frequent use of the latter in recent times, such as in the "International Year of the Disabled." On page 21 of the Report is reference to "stigma" being attached to the "disabled." In my opinion there is much more stigma attached to "handicapped."

It was disappointing, also, to note (page 22) the use of the unfortunately widespread term "deaf and hearing impaired." This terminology is incorrect. "Hearing impairment" is a generic term which includes all degrees of hearing loss, i.e., the categories of deaf and hard of hearing. The correct terminology as used by the various professional associations concerned with hearing impairment (Alexander Graham Bell Association for the Deaf, American Speech-Language-Hearing Association, Council on Education of the Deaf, etc.) is "hearing impaired (deaf and hard of hearing)." Similarly, "Blind and Vision Impaired" does not make much sense, although my friends in the field of vision impairment tell me that the term is currently acceptable to them.

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The report properly addresses this area in stressing the need for information systems such as NCHS, NARI and ABLEDATA working hand in hand with the Bureau of the Census. In this connection it is interesting to note (Washington Post, September 23, 1982 - Federal Report) that the administration has embarked upon a "Reform 88" management reform package which is purported to allow the Federal government to operate as "efficiently as a major corporation." The program includes 33 Senior Managers from 13 agencies. I strongly urge that programs for the disabled be included in this effort, incorporating some of the Options developed by the Report, to which I will refer later on in this testimony.

Consumer Involvement

The report repeatedly stresses in very specific ways the need for consumer involvement which is a continuation of trends evident over the past decade. It would seem that such involvement is essential in all areas of identification, planning, research and development, evaluation and delivery. Given the considerable number of specific disabilities encountered, and the tendency for people in each consumer area to be protective of their "turf," the report urges that program and project manager systems (p. 71) which encompass comprehensive technology assessment be established. (p. 82.) This implies assessment by groups which include disabled people who are able to recognize the needs of other disabilities.

At a personal level, my current membership on a Docent Training Manual team of the Department of Special Education for the Smithsonian Institutions is giving me considerable insight into other areas which include six major disability groups, e.g., hearing impairments, visual impairments, mobility impairments, emotional impairments, learning disabilities and developmental disabilities. All of these areas are represented by at least one member of the team, usually a person with the specific disability. Bringing all of these diverse areas into one workable document is a challenging task. It is enlightening, to say the least, to sit through a two-hour meeting in which three vision impaired persons discuss the concerns of their disability and appropriate entries in the training manual.

The Report has concluded (page 71) that "little of value has resulted from the money, time and efforts of the myriad research centers and programs supported by the Federal government," and points out (p. 170) that the "tactical goal of consumer involvement is "realism." Consumers and groups or organizations with which they interact should gain a more realistic appreciation of each others needs and capabilities." To accomplish a coordinated disability policy and program it would seem Options 2A and 2B could be combined to afford continuing oversight. The Report also sets up Policy Options 1,3,4 and 5 which, together with Option 2, encompass a broad, comprehensive set of objectives.

With so many options before it, Congress needs guidance from a central source which is able to focus on broad, impartial overview of the entire disability field. I would seem that the one group which, by its very title would be logical group to do so, is the National Council on the Handicapped. NCH is "mandated to review all policies and activities concerning disabled persons conducted or assisted by an Federal agency." (p. 123)

It seems somewhat unfortunate that NCH has been relatively ineffective for several reasons which include:

a) Its membership has been subjected to the winds of political change which have destroyed its continuity, and

2) Its funding is relatively modest, leading to limitations in its staffing and in the ability of members to meet together.

By statute NCH establishes policies for the National Institute for Handicapped Research, the "lead agency in evaluation of technologies for disabled people." It reviews the policies of the Rehabilitation Services Administration (RSA) which is mainly state oriented and funded.

To improve its effectiveness as a "National" Council, NCH needs to be charged with more specific oversight of all other areas in the Federal government which deal with disabilities. In order to accomplish this NCH must be removed from the political process and given adequate funding.

It would appear desirable to establish, as outlined in Options 1B and/or 1C, under NCH a joint public-or private corporation to provide identification, demographics, planning or appropriate technology, carrying out research and development, evaluation, marketing and diffusion, delivery, monitoring use, financing and finally, resource development and allocation. Such a chartered private, or public-private corporation would be eligible to receive federal grants, and state and private funding. Its primary focus would be at the state level, as sought in the current political climate, providing uniformity of operations among the various states, but be overseen at the national level by NCH for consistency in policy. As the Report suggests (p. 167) the Canadian Technical Aids and Systems for the Handicapped Inc. (TASH) should be looked into. On the other hand the models of the National Captioning Institute (NCI) and of Communications Sattelite Corporaticn (COMSAT) might suggest more effective ways of dealing with the situation. In any event disabled consumers would comprise a substantial percentage of the management of such an enterprise. The corporation could be started by RFP from a strengthened NCH, which would be the ultimate authority.

In conclusion I would urge that all areas of disability be brought together under the oversight of one body, such as NCH, which would have the ultimate composition, funding and authority from Congress to bring into uniform focus all efforts in the disability field.

Mr. SHAMANSKY [presiding]. Thank you, Dr. Breunig.

We have as our next witness Oral Miller, national representative for the American Council of the Blind.

Mr. Miller.

[The biographical sketch of Mr. Miller follows:]

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Oral O. Miller, A Biographical Sketch

Mr. Oral O. Miller, appointed National Representative for the American Council of the Blind in July, 1981, hails from Ashland, Kentucky. He received his A.B. degree from Princeton University, with a major in history. He was honored by the Class of 1955 at its 25th reunion as being the classmate to bring the most honor and luster to the class and Princeton University. In 1958, he earned his J.D. from the University of Chicago Law School, ranking in the upper-third of his class. In 1976, he was elected president of the American Blind Lawyers Association, a term which he held for two years. He is a member of the bar both in Kentucky and the District of Columbia. In 1974, Mr. Miller was named one of the "Outstanding Handicapped Federal Employees of the Year" by the United States Civil Service Commission.

Always interested in athletics and recreation (he was a member of the varsity crew squad at Princeton), he currently serves on the Committee on Recreation and Leisure of the President's Committee on the Employment of the Handicapped. He is a member of the Boards of Directors of the United States Association of Blind Athletes, Healthsports, Inc. and the American Blind Bowling Association.

Mr. Miller's direct involvement in national programs of the American Council of the Blind goes back to 1974, when he was named National Convention Coordinator, bringing him into contact with affiliates throughout the country. In 1976 he was elected to the ACB Board of Directors and served two years as Chairman of the Budget Committee. At the national convention in Salt Lake City, Utah, in 1978, Mr. Miller was elected president of the American Council of the Blind and in that position traveled far and wide representing the Council at meetings of the World Council for the Welfare of the Blind and in consultation with ACB affiliates regarding chapter and program development. Before assuming his duties as National Representative in August, 1981, he served for 18 years as a trial lawyer in the Office of General Counsel of the United States Small Business Administration in Washington, D.C.

Mr. Miller continues to serve on the Boards of Directors of many organizations concerned with the welfare of the blind and visually impaired. He is currently a director of the National Accreditation Council Serving the Blind and Visually Handicapped, the American Foundation for the Blind, the Columbia Lighthouse of the Blind, the Mississippi State University Rehabilitation Research and Training Center on Blindness and Low Vision and the Handicapped Concerns Standing Committee of the President's Committee on the Employment of the Handicapped.

September, 1982

Mr. MILLER. Mr. Chairman, I am Oral Miller, national representative of the American Council of the Blind which is the largest national organization of blind and visually impaired people in this Nation. We appreciate this opportunity to appear before you today to share our views concerning the Office of Technology Assessment's excellent report, "Technology and Handicapped People."

Our statement will focus on three areas as outlined in the report: Namely, research and development, consumer involvement and financial barriers to the acquisition of needed technologies.

One, research and development efforts should, whenever possible, stress applications of "off-the-shelf" technologies to meet the needs of disabled people.

About 20 years ago, the audio cassette tape was first introduced to the American consumer market. The earliest cassette tape recorder cost over $100, was bulky and lacked good sound quality by today's standards.

Yet, this new invention was the most important advance in communications for blind people since the invention of braille over 150 years earlier.

The cassette recorder soon became affordable, not because blind people bought these new devices, although many did, but because millions of sighted people around the world saw a use for this new technology. But the story of how the cassette tape recorder benefited blind people did not stop there.

As technology advanced, the four-track slow-speed cassette tape player has developed and today is used by thousands of blind and physically handicapped people who receive reading matter through the National Library Service for the Blind and Physically Handicapped of the Library of Congress.

This player, incidentially, is the half-brother to the standard, commercially-built stereo cassette deck which you probably have in your automobile.

Another spin-off from the bulky recorder of 20 years ago is the microcassette recorder, which is a cigarette package-sized recorder which many blind people find as indispensible for notetaking as you probably consider the pen in your pocket. I am referring to a recorder like this very one. Very small.

A further example is the Apple computer—no commercial plug intended—because it, when coupled with an inexpensive synthetic speech oscillator can speak in intelligible speech and it states whatever is seen on the screen by sighted users.

This system costs about $2,500, which is much less than half of the cost of most new automobiles nowadays.

Research never stands still and it shouldn't, but we believe that more attention should also be given to perfecting and completing existing technology rather than always looking over the research hill at the ultimate ideal breakthrough just ahead.

We certainly agree with OTA that consumers, along with production and marketing specialists should be involved in research and the application of existing systems at the earliest possible stage in order to ensure the development of useful devices that have a reasonable likelihood of reaching the ultimate consumer.

While researchers cannot and should not be told exactly what direction their research efforts should go, they should be encouraged, however, to give high priority to projects whether starting with them or others, which were not completed due to lack of funding materials and other reasons unrelated to the merit of the projects.

Second, consumer involvement should be mandated by Congress in all Federal or Federally-assisted research and development projects concerned with known disability-related technology.

Although it would be preferable for all Federal departments and agencies to establishing meaningful mechanisms for the solicitation and receiving of consumer input, we recommend that, for example, the Health Care Financing Agency, the National Institute of Handicapped Research, the Veterans' Administration and any other agencies concerned, should jointly establish and probably fund a committee of knowledgeable consumers that would be empowered to make a program-by-program review in order to determine which could use mechanisms to establish or expand that ever-important and essential consumer input.

This committee would not pass judgment on technical proposals, but it would offer suggestions to Congress and the agencies as to which programs lack effective consumer involvement and how that could best be achieved, such as through advisory panels, changing of makeup of existing committees, staff hiring and contracting with knowledgeable consumer organizations.

An Office of Consumer Involvement, without a clear mandate by Congress, that consumers must be involved is insufficient to meet the goal of effective consumerism. Consumer involvement on a programmatic basis would allow the selection of the most knowledgeable consumers with respect to the project involved and it would also assure that the same consumers would be involved at all stages of the technological development and delivery continuum.

Third, financial assistance through guaranteed low-interest loans or a similar program or some other means is needed to help disabled people acquire needed but generally expensive technological aids.

The American Council of the Blind, for example, receives inquiries from blind people throughout the country concerning the availability of financing for needed equipment, which makes work possible or more productive. But there are precious few such sources to be recommended.

The Versa Braille machine, for example, which could be used as a Braille word processor or as an input-output link in many computer applications, costs almost $7,000, which is well beyond the means of almost all blind employees who could benefit from using it.

In my opinion, the most limiting, handicapping, inconvenient and frustrating aspect of blindness is the inability to read the printed word. Yet, the only device now on the market which even approaches "reading" for the blind and converting it into intelligible synthetic speech costs almost $30,000, a price that individuals simply cannot pay.

In addition to a low-interest guaranteed loan program, Congress should consider providing tax credits for all or part of the purchase price of needed equipment by employers or employees who could not qualify under the loan program or who simply could not afford to pay a high price for a piece of needed equipment.

Finally, we believe that Congress should also consider the payment for needed technological aids under Federal health insurance programs, inasmuch as nonmedical technological aids can materially enhance the independence and productivity of disabled people.

The availability of such aids wouldn't necessarily guarantee jobs for all disabled people, but would help them compete for jobs based on their ability.

In conclusion, we of the American Council of the Blind stand ready to do our part in assisting the Government in attaining the goals of effective consumer involvement in the development, manufacture, and distribution of disability-related technology.

Through our 67 State and special interest-affiliated organizations, we can provide knowledgeable input from blind professionals, teachers, students, businessmen, and other individuals from an enormous variety of backgrounds, and we certainly look forward to working with Congress and others in this area.

Thank you very much.

[The prepared statement of Mr. Miller follows:]

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U.S. SENATE COMMITTEE ON LABOR & HUMAN RESOURCES

AND

U.S. HOUSE COMMITTEE ON SCIENCE & TECHNOLOGY
SUBCOMMITTEE ON SCIENCE, RESEARCH & TECHNOLOGY

STATEMENT OF

THE AMERICAN COUNCIL OF THE BLIND

BY

ORAL O. MILLER
NATIONAL REPRESENTATIVE

ON

TECHNOLOGY OF THE HANDICAPPED:
A REPORT OF THE OFFICE OF TECHNOLOGY ASSESSMENT,
U.S. CONGRESS

SEPTEMBER 29, 1982

Mr. Chairman: The American Council of the Blind is the largest national organization of blind and visually impaired people in this nation. We appreciate this opportunity to appear before you today and to share our views concerning the Office of Technology Assessment's excellent report, Technology and the Handicapped. Our statement will focus on three areas as outlined in the report: namely, research and development, consumer involvement and financial barriers to the acquisition of needed technologies.

I. RESEARCH AND DEVELOPMENT EFFORTS SHOULD, WHENEVER POSSIBLE, STRESS APPLICATIONS OF "OFF-THE-SHELF" TECHNOLOGIES TO MEET THE NEEDS OF DISABLED PEOPLE.

About twenty years ago, the audio-cassette tape was first introduced to the American consumer market. The earliest cassette tape recorder cost over one hundred dollars, was bulky and lacked good sound quality by today's standards. Yet, this new invention was the most important advance in communications for blind people since the invention of braille over 150 years earlier.

The cassette recorder soon became more affordable -- not because blind people bought these new devices, although many did -- but because millions of sighted people around the world saw a use for this new technology. But the story of how the cassette tape recorder benefited blind people did not stop here!

As technology advanced, the four-track slow speed cassette tape player has developed and today is used by thousands of blind and physically handicapped people who receive reading matter through the National Library Service for the Blind and Physically Handicapped of the Library of Congress.[7] Another example of a useful device which represents a spin-off from the original cassette technology, is the microcassette: a cigarette-sized tape recorder which many blind people find as indespensible for notetaking as the pen in your pocket.

My point is this: research and development efforts should, whenever possible, be aimed at using standardized "off-the-shelf" technology. It seems to us that the use of standardized hardware to meet the needs of disabled people will reduce the cost of needed technologies. An example of this is the Apple II Plus computer which can be equipped to talk for a relatively small incremental increase in the purchase price.

We agree with the recommendation of the Office of Technology Assessment that consumers as well as production and marketing specialists should be involved in research and development of new and applied technologies at the earliest possible stage. We further agree with OTA that the addition of consumers, production and marketing personnel to the development team will help to ensure that research and development will be aimed at the creation of useful devices which have a reasonable likelihood of reaching the ultimate consumer.

Although we appreciate that much research and development is devoted to the creation of high-technology items, we also believe that emphasis should be placed on the development, manufacture and dissemination of low-technology, low-cost devices which have great utility to disabled people. Examples of this kind of technology include simple audio circuits which make visual meters and other measuring instruments accessible to blind people, thereby opening a myriad of job opportunities in the trades, technical and scientific fields.

II. CONSUMER INVOLVEMENT SHOULD BE MANDATED BY THE CONGRESS IN ALL FEDERAL PROGRAMS OR FEDERALLY ASSISTED PROGRAMS CONCERNED WITH THE DEVELOPMENT AND USE OF DISABILITY RELATED TECHNOLOGIES.

As noted earlier, consumers can and should play an important role in the development of disability related technologies. Congress should expand the formal statutorily-based requirements for participation of disabled people at all stages of the technology pipeline. Agencies such as the Department of Health and Human Services, the Veteran's Administration, the Department of Education, the Department of Labor and the Small Business Administration should be required to involve disabled people directly and to support consumer activities.

A strong commitment to consumerism by the Congress is necessary if the goal of effective consumer involvement is to be achieved. Effective consumer input is sometimes difficult to achieve because of the attitude of professionals, the bureaucratic resistance to another layer of review and because we currently lack appropriate mechanisms to ensure that consumer involvement will be a part of the technology delivery system.

We recommend that the Health Care Financing Agency, the National Institute of Handicapped Research and the Veteran's Administration should jointly establish and fund a committee of consumers which would be empowered to make a program-by-program review to determine which programs could best use various mechanisms for establishing or expanding consumer involvement. This committee, composed of individuals and representatives of consumer organizations would not pass judgment on particular technologies. Rather, the committee could offer suggestions to the Congress and to the Executive Branch as to which programs are lacking effective consumer involvement and how effective consumer input can best be achieved through a variety of mechanisms including, but not limited to, consumer advisory panels, staff hiring and contracts with consumer groups.

We doubt that any voluntary effort to establish or expand consumer input will be successful. An office of consumer involvement without a clear mandate by Congress that consumers be involved on a programmatic basis is insufficient to meet the goal of effective consumerism.

In addition, we believe that it would be difficult to assemble in an office of consumer involvement a cadre of talent sufficient in breadth and experience to evaluate proposed technologies. By contrast, consumer involvement on a programmatic basis, allows for selection of the most knowledgeable consumers with respect to the particular program in question and also ensures that the same consumers will be involved at all stages of the technology delivery continuum. Sharing of information among agencies is, of course, necessary and could be one of the responsibilities of the consumer committee discussed earlier.

III. FINANCIAL ASSISTANCE THROUGH GUARANTEED LOW INTEREST LOANS AND OTHER MEANS IS NEEDED TO HELP DISABLED PEOPLE ACQUIRE NEEDED TECHNOLOGIES.

Financial barriers put many useful technologies beyond the reach of most disabled people, thus limiting the potential market for these devices.

Many disabled people have sufficient resources to disqualify them from participating in programs that pay for needed technical items. The American Council of the Blind receives frequent inquiries from employed blind individuals concerning the availability of financing for needed equipment which makes work easier or more productive. A VersaBraille unit, for example, would be extremely useful to many blind employees as a stand alone word processor or as an input/output link in many computer applications. Yet this device costs approximately $7,000.00, which is well beyond the means of almost all employees who could benefit from this technology. Other items such as talking computer terminals, reading machines and braille printers can cost upwards of $20,000.00. There are few sources of available financing for this equipment.

We endorse OTA's suggestion that Congress mandate a loan guarantee program featuring low interest financing to assist disabled people to obtain needed technologies. In addition, Congress should provide a tax credit for all or part of the purchase price of needed equipment for those who could not meet the requirements of the loan program. Tax credits could also benefit employers who purchase needed technologies for their employees.

Finally, we also believe that Congress should consider payment for needed technologies under Federal health insurance programs. Non-medical technologies can materially enhance the independence and productivity of disabled people and, accordingly, such items should be made available under Federal health insurance programs. We agree with OTA's observation that expenditures for such equipment represent a long-term cost savings to the government, as compared to the cost of welfare and other support programs. The availability of needed technologies will not guarantee jobs for disabled people, but will help such individuals compete for jobs based upon their abilities.

IV. CONCLUSION

The American Council of the Blind stands ready to do its part to assist government in achieving the goal of effective consumer involvement in the development, manufacture and dissemination of disability related technologies. The American Council of the Blind, through its sixty-seven state and special interest affiliated organizations can provide consumer input from blind professionals, students, teachers, business people and individuals. We look forward to working in partnership with others toward improving the technology delivery system to the benefit of all disabled people.

Mr. **Walgren** [presiding]. Thank you very much, Mr. Miller.

Thank you all very much for your presentations. We will now hear from the next panel.

STATEMENTS OF JAN LITTLE, EXECUTIVE VICE PRESIDENT, CHIEF EXECUTIVE OFFICER OF MEDICAL EQUIPMENT DISTRIBUTORS, MAYWOOD, ILL.; JAMES C. BLISS, PRESIDENT, TELESENSORY SYSTEMS, INC., PALO ALTO, CALIF.; AND BARRY ROMICH, PRESIDENT, PRENTKE ROMICH CO., SHREVE, OHIO

Mr. **Walgren**. As with the other witnesses, your written statements will be made part of the record. We will start with Ms. Little. Welcome to the committee. We are glad you are here. Please proceed.

[The biographical sketch of Ms. Little follows:]

CURRICULA VITAE

Janet E. Little, B.S, M.S.

Present address: 20 North Tower Road
Oak Brook, Illinois 60521

Current position: Executive Vice President and CEO
Medical Equipment Distributors, Inc.
1701 South First Ave.
Maywood, IL. 60153

Medical Equipment Distributors, Inc. is a national company specializing in delivery of rehabilitation equipment, home health care equipment and inhalation therapy services. The company has forty-five locations. Each location features full showroom, sales force, warehouse inventory and repair services.

Prior employment

1961-1966: Assistant Supervisor, Occupational Therapy and Special Services, Rehabilitation-Education Center, University of Illinois, Champaign, Illinois.

1966-1968: Managing Editor, National Sporting Goods Association, Publications Division, Chicago, Illinois.

1968-1971: Managing editor, Allured Publishing Co., Oak Park, Illinois.

1971-1974: General Manager, Medical Equipment Distributors, Inc., Forest Park, Illinois.

Education

Janesville High School, Janesville, Wisconsin - graduated-1957
University of Illinois, Urbana, Illinois, B.S. Journalism-1961
University of Illinois, Urbana, Illinois, M.S. Communications-1965

College Activities

Student Government, Top 100 Seniors, Harold Scharper Service Award, wheelchair sports.

Other Activities

Member, U.S. Wheelchair Team, Stoke-Manderville, England, 1962.
Member, U.S. Wheelchair Team to South Africa, Rhodesia, Nyasaland, 1962.
Member, U.S. Wheelchair Team to Stoke-Mandeville, England, 1963.
Member, U.S. Paralympic Team to Tokyo, Japan 1964.
Member, U.S. Wheelchair Team to Stoke-Mandeville, England, 1966.
Vice President, National Spinal Cord Injury Foundation 1972.
Founding member, Rehabilitation Engineering Society of North America - 1979
Secretary/Treasurer, Rehabilitation Engineering Society of North America, 1979-1982.
Member, Panel on Science and Technology for the Disabled, U.S. House of Representitives Committee on Science and Technology, 1977-1978.
Presenter, Wheelchairs I, sponsored by NIHR and Veterans of Administration 1977.
Speaker and presenter Wheelchairs II, sponsored by NIHR and Veterans Administration 1979.
Co-Chairman, RESNA workshop on wheelchairs, 1981
Participant, Wheelchair III sponsored by Veterans Administration, 1982.

Ms. LITTLE. Thank you, Mr. Walgren.

I would like to correct my title for the record. It is executive vice president, chief executive officer of Medical Equipment Distributors.

I have already submitted lengthy testimony regarding technology and the handicapped and why technology is not reaching the handicapped.

I suppose you are not supposed to be flip in a Senate and House hearing, but there are many times these days when I feel my current handicap is being the chief executive officer of a company whose business depends on reimbursement from Federal agencies for purchase of products for the disabled.

Technology is not being delivered to the handicapped for a number of reasons. There is a lack of definition of appropriate application of technology. Many of the previous presenters have spoken of the need for consumer input to the manufacturing and distribution community and we do need this input but we do need coordinated, defined input.

Some has been given and some products have resulted from this.

Representing industry, I urge that consumers develop coordinated and realistic applications of technology, and industry will be interested in that input.

I firmly believe, as a person who has a disability and as a person who is in business, that we must involve the private sector in delivery of technology to the handicapped.

At the moment, there is a huge lack of incentive to the private sector to become involved. Not only are goals not defined, but the private sector does operate on a for-profit basis or it will disappear.

In this country, this has been the basis of our society, the business and profit motive.

Our particular industry, which is in charge of delivering technology to the handicapped, is inhibited by the Federal-State methods of reimbursement for services and equipment to the disabled.

For example, our funds for research and development in private industry in the durable medical equipment and technological aids are very limited. Our equipment and our products are priced by what we receive from medicare and medicaid and third-party insurers.

This unfortunate situation has also traveled over into other areas which provide reimbursement for disabled. That is private insurance.

To cite one example, HCFA, which is the Health Care Financing Administration, states that bathroom and toilet aids are not a medical necessity, under some portions of medicare. We are now finding private insurance agencies are also considering that these are not medical necessities.

Items which will prevent further disability, such as an attachment to a power wheelchair that will allow a person to change their position and prevent a pressure sore which may cost $20,000 to $30,000 to heal is not a medical necessity.

We may not prevent problems. We also find that because of this attitude which has come down to support the handicapped, we have grave problems introducing new technology, not only to the recipients but to the people who prescribe this, the therapists and the doctors. It is almost impossible to introduce it to the people who should be paying for it.

One of the gentlemen previously mentioned the Apple computer. I have been involved with, at arm's length, several disabled individuals who could have become employed if they could have an Apple computer, but their only source of funding was through welfare and medicaid and there is no way you can get an Apple computer through medicaid.

In Oklahoma, we finally went out and put on a benefit and the townspeople raised the money for this person. I would also mention that once this equipment is approved, there is a long wait for the authorization.

We recently had a power wheelchair system, identical to Margaret Pfrommer's, held up for 2 years until we could get reimbursement, or get authorization rather, from Blue Cross-Blue Shield, the medicare carrier in the State of Indiana.

Private industry is not being helped along by the length of time it takes to receive payment, either. Hopefully, there is action before Congress that we may charge a service charge for payment after 60, 120, or more days.

From my point of view, I am afraid that the individuals with severe handicaps are, to use a current phrase, falling through the crack in the funding agencies and service delivery systems.

There should be some way that the people who authorize funding can learn that there is a difference between a young man who at the age of 21 severs his spinal coard at the second or third vertebrae and becomes a quadraplegic, and the medicare-medicaid case who is 65 or 66, or older.

There seems to be no awareness that the young disabled do have a potential. If it is not a potential for immediate employment, it is a potential for improved quality of life.

I would like to respond to something you mentioned, Mr. Walgren. I have seen in a number of institutions where technology is an incentive and a motivational factor to an individual.

In my company, we deal very frequently with the high-level quadraplegics, as soon as they enter the rehabilitation facility.

We frequently find that if a young man or woman who has suddenly awakened one morning and can't even scratch their own nose, can't do anything, can't even leave the room if they don't like the company, and if you do at that point give them a power chair which they can control with their tongue or by sipping or puffing, an environmental control which independently allows them to change the channel on their television, this is a motivational factor to that individual, because he or she no longer thinks, "I am going to be stuck in bed the rest of my life, not even being able to leave the room if I don't like the people in it."

I think that another matter that should be considered is that the handicapped be allowed to have sliding support from the welfare programs. I am not totally familiar with the facts, but I have heard from a number of people that if a handicapped person makes a portion of their living, their welfare payments may be revoked.

It seems economically unfeasible to me to spend $40,000 to totally care for a person when that person with the proper technology could earn $15,000, or $20,000, or $25,000 toward their own support.

Maybe they won't quite make it to the point where they could live comfortably on their salary, because handicapped people do need additional things.

I am one of the fortunate. I can afford to live in a very nicely accessible house. I can afford to drive the kind of car that has been suited to my needs. I can afford to use the airlines freely. But many people can't drive a car; they do need some type of transport; they do need accessibility; they do need an attendant. And if they could be allowed to earn their living, it would not only be a reduction of cost to the government, it would be a tremendous step toward personal worth and humanity.

In closing, I would like to say that we, who are in the industry, are a small group and rather close, and we stand ready to help, but we need help to help the handicapped.

Thank you.

[The prepared statement of Jan Little follows:]

Testimony before the U.S. Senate Committee on Labor and Human Resources and the U.S. House Subcommittee on Science, Research and Technology, of The Committee on Science and Technology
September 29, 1982

Jan Little
Executive Vice President
Medical Equipment Distributors, Inc.

TECHNOLOGY AND THE HANDICAPPED:

The slogan for a recent rehabilitation engineering conference, "Technology that enables" was criticized by many disabled consumer advocates. Their contention was that very little of the current high technology available is put to use to help those with physical disabilities such as limited mobility, sensory impairments or inability to speak. "If we can put a man on the moon, why can't we eliminate disability?" is a question frequently posed to those of us who work in the area of technology and rehabilitation equipment.

We know the needs exist. In many instances, present technology is being utilized to solve various problems ranging from lighter-weight wheelchairs to sensory aids to implants to replace lost nerve functions. An amazing amount of technology developed in recent years has been applied to the needs of people with disabilities. However, the applications have not been fast enough to answer the urgent needs of the individuals who might depend upon the technology. Nor, in many categories, has the technology been made widely available to those in need.

Why application of technology moves slowly

Four major factors effect the rate at which advanced technology is applied to needs of the disabled: Demand, Definition, Resources and Delivery System. These factors, rather than willingness and intention, have hindered technological advancement.

Demand: The United States is geared to mass production and mass marketing. Sophisticated consumer products, such as miniaturized calculators and home computers are an example of demand lowering price and increasing availability. The demand for rehabilitation equipment incorporating advanced technology is small. The size of the market is not encouraging to manufacture of sophisticated products. Relatively small production runs inherently raise costs through such factors as electronic components being a fraction of the cost if purchased by the thousands over the cost of purchasing several hundred. The cost of development to the manufacturer is also more burdensome in this industry than in many others. Amortizing $500,000.00 worth of molds or tooling over several thousand--or several hundred--products per year is a cost few manufacturers can bear. In consumer products, such as appliances, these costs could be amortized against perhaps a million products per year. To add to the problems, the specifications for products for the disabled may be highly customized to suit the individualized needs of the end user.

Definition: Before application of technology can occur, the uses made of the technology must be defined. Again, the technology for handicapped market presents unusual problems. Much of the equipment, such as wheelchairs, are prescribed or chosen by someone other than the end user. For many years, little user input on a product as relatively simple as the wheelchair was relayed to the developers of new design. Only since the return of disabled veterans from Viet Nam have disabled consumers become vocal about their needs and taken a role in defining the products which will suit their needs. Even now, because the needs of the product users vary, input to define needed applications of technology are fragmented and not strong enough to exert significant influence.

Resources: Funds and scientists are critical ingredients to application of technology in any industry. Factors such as the size of the market and limitation of equipment prices because of third party payer purchases have resulted in less funding available for research and development than is found in pharmaceuticals, automotives, appliances and other industries. People are also less available in our industry. There is little incentive for top electronic, mechanical or other engineering graduates to enter into research in this industry. Although there are many dedicated researchers in the field loosely termed rehabilitation engineering, we frequently see promising researchers forced to go to Xerox, Bell Labrotories and other industries because there are no funds to support their research in rehabilitation equipment.

Delivery System: A strong influence on application of technology is the "Catch 22" of the delivery system. Setting aside the fact that most third party payers shy away from new products and expensive products, we are still left with the fact that many types of advanced technology are difficult to handle. While power wheelchairs are becoming more prevalent, the service and maintenance of this product is a major problem for the user. Although more DME companies are developing competant repair and service facilities, service still presents problems to the dealer. The power wheelchair user's entire mobility and in independence is reliant on his wheelchair. This makes the dealer's responsibility far greater than that of the local auto mechanic. In more advanced technology, fewer dealers are familiar with the equipment and less able to handle it. Because product introduction frequently occurs through the dealer network, new product introduction and development of a market are inhibited by lack of dealer knowledge. This limits the number of products the manufacturer will sell, lessening his profit and allowing him to do less dealer training.

Research Resources

The less than ideal climate for research in rehabilitation equipment does not mean that such research is not being done. In addition to some excellent R & D being done by some manufacturers, there are a number of sources of research. Some application of technology developed during the "Space Race" is still being transferred to aid the disabled by the NASA Biomedical Applications Teams (BAT). Notable contributions have been made by BAT in the areas of urinary collection devices, non-latex foams and control technology.

Government funding in rehabilitation engineering exists in 16 Rehabilitation Engineering Centers located across the country. These REC's, funded by the National Institute for Handicapped Research and the Veterans Admininstration, have been assigned specific areas of research such as communications, joint replacement, workstation evaluation, wheelchair research and other core areas relating to specific problems. In addition, most of the REC's are connected with rehabilitation facilities and do one-on-one work with patients at these centers. Important applications of technology have come from these REC's and moved into the commercial market place. Among these products are reading devices for the blind, the Autocom electronic communicator, MPI seating system for children with cerebral palsy and numerous control systems for power wheelchairs, In addition, some of these REC's are now coordinating with major manufacturers to augment research and testing facilities of the manufacturers.

Several Rehabilitation Engineering Programs have become involved in the service delivery system. Community programs have been or are being conducted at Southwest Research Institute, San Antonio, Texas; Stanford University, Palo Alto, California; and Moss Rehabilitation Center, Philadelphia, Pennsylvania. These programs have specilized in areas including equipment specification and modification, home evaluation and job site evaluation.

Participants in technology application

Given the nature of technology for the handicapped--the small market, lack of economic incentive, limitations on funds for development and the high degree of specialization and customization, a different approach has been necessary to apply technology to the needs of the disabled. Consumer knowledge and demand are minimal. To cite an example, television manufacturers have made great strides in such areas as video recorders, home electronic games and video accessories. These products resulted from a consumer demand and a high level of competition in the marketplace. Most consumers of rehabilitation equipment lack knowledge of the products available. Many have little idea of improvement or changes that could be made and do not pressure for these changes. Unlike the television industry, the medical equipment industry does not have the reinforcement of mass media advertising to educate consumers and create demands for new products. Manufacturers in the DME industry are beset by a flood of government regulations which absorb some funding and energy which might to research. Dealers frequently are more concerned -- as a matter of survival-- about reimbursement for their services than application of new technology.

This picture may be changing. Wheelchair sportsmen and sportswomen brought about the demand for better racing wheelchairs. When they could not buy these wheelchairs from major manufacturers they made the chairs themselves. The recent entry of small companies such as Quadra, Production Research and Motion Design Systems, Inc. into the wheelchair market have provided an incentive for the major wheelchair manufacturers to produce sports wheelchairs. In addition, some of the major wheelchair manufacturers have begun to incorporate features used in sports wheelchairs, such as sealed precision bearings, adjustable axle positions, adjustable seat angle and variable back height into wheelchair lines designed for the average user.

Participation in application of technology has been aided by conferences which brought together representatives of rehabilitation engineering, medical fields, users of wheelchairs and manufacturers. Beginning in 1977, a series of conferences, sponsored by the Veterans Administration and NIHR (Wheelchair I - Manual Wheelchairs, 1977; Wheelchairs II - Power Wheelchairs - 1979 and Wheelchairs III-Sports Wheelchairs and Power Wheelchairs for the Severely Disabled, 1982) have produced results. Most of the recommendations resulting from Wheelchairs I have been incorporated into wheelchairs such as the Quadra, Stainless Medical Products' Super Star and Invacare's HPL. Many of the recommendations resulting from Wheelchairs II have been included in the design of the Invacare Rolls IV Power Chair and the work done by Twentyfirst Century Scientific, Inc. Such features as automatic course correction, regenerative braking and greater power and speed are now commercially available. These features had long been technically possible, but lack of feed-back and, to some degree, lack of competition, inhibited the expenditures necessary to bring them to the market.

The areas of communications and sensory dysfunction will attract more of the manufacturers now serving the field of consumer electronics. However, this will not solve all of the problems involved in delivery of service to the end user. Distributors of consumer products are not equipped to deal with the tremendous load of paper work required by those parties who fund handicapped individuals. Nor are such distributors prepared to deal with clinical settings for evaluation of these products.

In addition to the requirements for procuring funding for this equipment, there is a need for ready service of these highly technological devices. This service would be most logically be given through private industry; specifically the durable medical equipment industry. Private industry, in the form of dealers, can serve the needs of the handicapped individual on the local level.

It seems unrealistic to try to super-impose the service needed by the handicapped on to an existing industry other than that industry which delivers medical equipment at this time. The competition which is traditional to private industry would promote better service to the disabled if the economic incentive were present. To date, drawbacks to the expansion of this industry have included economic incentive and difficulties of dealing with the funding agencies. Our company has experienced delays of up to two years in funding of equipment for handicapped persons through Medicaid/Medicare carrier Blue Cross/Blue Sheild.

This same network of private enterprise can serve as evaluation units through their showrooms and through loan of equipment to rehabilitation centers. Much of the missionary work necessary to introduce new products can also be conducted through this network.

There now exists a sizeable network of private enterprise serving what is termed the Home Health Care market. This market is somewhat different than that which could serve to deliver high technology to the handicapped. Traditionally the Home Health Care market has depended upon low margins because of competition and because of the method of reimbursement for their services. One recomendation would be to separate rehabilitation products from home health care products. Even though these products will overlap in some areas such as wheelchairs, bathroom devices and aids to daily living, the more highly technical products such as environmental control, power wheelchairs and communication devices must be recognized as a separate product area. This product area must be broken out of the funding requirements for home health care. Agencies funding such products would have trained personnel on their staffs who could recognize the technical items and the use to which these technical items would be put. Frequently, we now see communications devices and environmental control disallowed by the funding agencies because they are not a medical necessity. If these products were broken out of the durable medical equipment classification they could be treated in a manner which assure delivery to the handicapped user.

Until some measures are taken by the Federal Government, which does control Medicare/Medicaid, to provide technology to the handicapped on a different basis then has been previously used, delivery of technology to the handicapped people will suffer. We see other funding agencies and private insurance companies beginning to follow the guidelines of Medicare/Medicaid, thus denying any support for delivery of technology to the handicapped.

This is not necessarily a recomendation for a new agency or for further bureaucracy. It is a recommendation for the needs of the severely handicapped to be considered as different from those of the aged or infirm. Some differentiation must be made between the young person with a severe disability who has the potential to be employed and the person who is simply living out his years in a geriatric setting. Provision of highly technical products to those who are either entering their wages earning years or who are only a short way into their wage earning years would result in lessened cost to the government over the long run. An example of this might be a quadreplegic who, with the provision of a power wheelchair operated by sip and puff and environmental control system which allows him to operate a computer, may work as an insurance actuary. Along with the provision with the equipment the government must consider a sliding scale of support for the physically handicapped. At the moment many severely handicapped individuals are not capable of earning wages which will allow them to hire the attendent they need nor to have the transportation that they need. Because of this situation many disabled people who could make $15,000, $20,000 or $25,000 a year must remain on welfare because if they do earn any money they will lose their government allowances. How much more economic sense it would make to allow these individuals to earn a part of their living and receive enough in additional support to allow them to live independently and to contribute to society rather than to live out their lives as welfare recipients and burdens on that society.

The delivery of technology to handicapped people must be addressed in three areas. Economic incentive must be given to the private sector to provide technology to the handicapped individual. A private enterprise based service delivery system must be encouraged through changes in the laws which reimburse vendors for delivery of service and products. A sliding scale support for living must be developed for the severely handicapped so that they may gradually work their way into the mainstream of society.

Mr. **Walgren**. Thank you very much. Your remarks are right on target. We will now hear from James Bliss, president of Telesensory Systems, Inc.

[The biographical sketch of Mr. Bliss follows:]

BIOGRAPHICAL SKETCH

James C. Bliss, Ph.D.
President
Telesensory Systems, Inc.
Palo Alto, California 94304

Dr. James C. Bliss, President of Telesensory Systems, Inc., has been active in the development of technology for the blind and physically handicapped since his graduate work at MIT from 1958 to 1961. During the 1960's, Dr. Bliss continued this work with Stanford Research Institute as Manager of the Bioinformation Systems Group and as Associate Professor of Electrical Engineering at Stanford University. It was during this period that he first began working on the development of optical-to-tactile image conversion devices for the blind which led to design work on the Optacon in conjunction with its inventor, Prof. John Linvill, former Chairman of the Electricl Engineering Department of Stanford University.

As President of Telesensory Systems, Inc. since 1970, Dr. Bliss has guided the manufacture and distribution of the Optacon from the original order for 50 machines from the U.S. Office of Education to the present 9000th Optacon. With some 150 employees in the company and products in 64 countries throughout the world, Dr. Bliss continues to devote all of his time and energy to the development and delivery of technology for blind, hearing impaired, and non-vocally handicapped individuals.

Dr. Bliss received his BS in Electrical Engineering from Northwestern University, his Masters in Electrical Engineering at Stanford University, and his Doctorate in Electrical Engineering from MIT. He has been the author of numerous papers and articles which have appeared over the past several years in a variety of professional and topical publications; he is the holder of several patents, a member of IEEE, AEVH, AAWB, and CEC, was the 1978 recipient of the Isabelle and Leonard H. Goldenson Award for Outstanding Scientific Research in Technology for Cerebral Palsy and the Physically Handicapped, and the 1980 co-recipient (with Dr. John Linvill for invention and development of the Optacon) of the City of Philadelphia Board of Directors of City Trusts John Scott Award.

September 21, 1982

Dr. BLISS. I appreciate the opportunity to testify before these two committees. I would like to comment on the Office of Technology Assessment report and to relate the OTA findings to the experience of Telesensory Systems, Inc., in providing useful cost-effective technological aids to blind and nonvocally handicapped individuals over the past 11 years.

Telesensory Systems, Inc. [TSI] is a small business—less than 150 employees—which was established in 1970 to make high technology aids available to handicapped people. TSI manufactures and markets the Optacon, a hand-scanned, portable reading aid for the blind, the VersaBraille, an electronic information-processing system for the blind based on braille, and the Crib-O-Gram, an auditory screening system for newborn infants. TSI also markets the Canon Communicator in the United States, a very small, portable communication aid for people who cannot speak intelligibly.

About 9,000 Optacons are now in use in 64 countries around the world. The Optacon can have a significant impact on the educational and vocational development of a blind person, as well as his independence in everyday living. Almost all of the Optacons have been purchased by funding sources other than the individual user for application on the job or in schools. In many cases the Optacon has been essential for job performance by a blind person.

In 1980, we introduced the VersaBraille information system, a portable, microprocessor-based system which greatly facilitates braille reading, writing, and information handling by storing both braille and audio information in electronic form on cassette tapes in a way that can be easily retrieved.

Most importantly, the VersaBraille provides convenient, automatic translation between braille and inkprint text. The VersaBraille has greatly increased the productivity of many employed blind persons, especially office workers. Application of the VersaBraille in educational situations has shown that it can be an important tool in enabling a blind student to obtain, process, retrieve, and compose text material.

We agree with the OTA finding that the current finding of diffusion to the handicapped community suffers from a number of significant weaknesses.

During the decade of the seventies, there was a climate which produced significant progress toward the application of technology to bring handicapped people into the mainstream of society by enabling them to lead more productive and independent lives.

However, since the beginning of 1981, there has been a dramatic change in the United States regarding technology and handicapped people. The agencies and programs providing funding for the purchase of sensory and communicative aids have been terminated or the budgets have been severely reduced.

For example, today, of all the Optacons manufactured, only 22 percent are destined for the United States.

The remaining 78 percent are sold outside the United States. This is a drastic change from the period 1971 to 1980, in which 70 percent of the Optacons manufactured were sold within the United States.

This reduction in U.S. application of technology for handicapped individuals is a direct result of severe reductions in U.S. Government social service programs without the establishment of adequate replacement funding sources.

Today, it is a tragic injustice, I believe, that American technology is not reaching the U.S. citizens who need it nearly to the same extent as it is to their counterparts in the disabled communities of Sweden, Holland, Italy, Japan, and many other countries of the world.

We agree, also, with the OTA report in that there are major weaknesses which existed before the budget cuts in the program. One of these weaknesses is the drastic State-to-State variations in the technology diffusion policies.

Another weakness is excessive bureaucracy and overhead in the delivery system, as Jan Little has mentioned.

Another weakness mentioned in the OTA report, which we agree with, are the gaps in the system which leave out segments of the handicapped population for no logical reason.

For example, often it is impossible for a college student to obtain a sensory aid which would be of enormous help in preparing for his vocation. Since sensory and communication aids are not covered by medicare and medicaid because they are not considered medically necessary, there is little or no hope for large segments of the handicapped population to obtain funding for an aid.

Only if you are a veteran or if you are unemployed and an aid is necessary for employment, and you live in the right State, is there a chance for provision of the needed technology.

When these systems' weaknesses were coupled with the subsequent budget cuts, an already defective system was rendered largely inoperative even though many of the administrative costs continued.

In addition, great market uncertainty was created in the private sector, which discouraged investment and innovation.

The OTA report describes some possible options for improvement of this system. We support some of these options and believe there are more options which should be considered.

Option 1-A of the OTA report is to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in production and marketing. We agree with this option. We feel the most important action Congress can take are steps which would lead to the creation and stimulation of a U.S. market of technology for the handicapped.

Some ways in which this could be done are: By the creation of tax credits to disabled individuals to purchase technology; by the creation of a program which would guarantee low-interest loans, as described in option 4-A of the OTA report; and by the expansion of medicare-medicaid programs, as described in options 4-B and 4-C of the OTA report, to include devices that are needed but not presently deemed as medically necessary.

These actions attack the problem at the source, which is lack of purchasing power of disabled people. The OTA report states that 60 percent of disabled adults of working age earn incomes at or near the poverty level. Of 15 million disabled Americans between the ages of 16 and 64, more than 7.7 million are either out of the labor force because of choice or unemployment.

These recommendations, tax credits for sensory and communication aid expenses, guaranteed low-interest loans, and medicare-medicaid reimbursement policy changes, if enacted, can create a market which would lead to an effective and efficient system for delivery of appropriate technology for handicapped people.

This market could then justify and provide the impetus for addressing the remaining issues and options identified in the OTA report: R&D, trained personnel, evaluation, and financing barriers.

Thank you.

[The prepared statement of Dr. Bliss follows:]

HEARING TO REVIEW THE OFFICE OF TECHNOLOGY ASSESSMENT REPORT "TECHNOLOGY AND HANDICAPPED PEOPLE

Senate Committee on Labor and Human Resources
House Committee on Science, Research and Technology
September 29, 1982
Room 2318 Rayburn Office Building
Testimony Presented by Dr. James C. Bliss, President
Telesensory Systems, Inc.
Palo Alto, CA 94304

Mr. Chairman, I appreciate the opportunity to testify before these two committees. I would like to comment on the Office of Technology Assessment Report and to relate the OTA findings to the experience of Telesensory Systems, Inc. in providing useful, cost effective, high technology aids to blind and non-vocally handicapped individuals over the past eleven years.

Telesensory Systems, Inc. (TSI) is a small business (less than 150 employees) which was established in 1970 to make high technology aids available to handicapped people. TSI manufactures and markets the Optacon, a hand-scanned, portable reading aid for the blind, the VersaBraille, an electronic information processing system for the blind based on braille, and the Crib-O-Gram, an auditory screening system for newborn infants. TSI also markets the Canon Communicator in the United States, a very small, portable communication aid for people who cannot speak intelligibly.

About 9000 Optacons are now in use in sixty-four countries around the world. The Optacon can have a significant impact on the educational and vocational development of a blind person, as well as his independence in everyday living. Almost all of the Optacons have been purchased by funding sources other than the individual user for application on the job or in schools. In many cases the Optacon has been essential for job performance by a blind person.

In 1980 we introduced the VersaBraille information system, a portable, microprocessor-based system which greatly facilitates braille reading, writing, and information handling by storing both braille and audio information in electronic form on cassette tapes in a way that can be easily retrieved. Most importantly, the VersaBraille provides convenient, automatic translation between braille and inkprint text. The VersaBraille has greatly increased the productivity of many employed blind persons, especially office workers. Application of the VersaBraille in educational situations has shown that it can be an important tool in enabling a blind student to obtain, process, retrieve, and compose text material.

Our experience with these products is consistent with OTA's finding that the current system of diffusion of technology to the handicapped community suffers from a number of significant weaknesses. During the decade of the seventies there was a climate which produced significant progress toward the application of technology to bring handicapped people into the mainstream of society by enabling them to lead more productive and independent lives. This progress has tended to benefit all parties involved: handicapped people, employers, government, and society in general. A key to this progress has been the creation of a market which has stimulated technical innovation and a small industry to provide appropriate technology.

In the case of TSI's products, this newly created market was heavily dependent on government funding. Even though no government agencies or programs were specifically mandated to fund the purchase of these aids, government funding developed because of the clear success these aids produced in obtaining appropriate education and employment for the target population.

Since the beginning of 1981 there has been a dramatic change in the U.S. regarding technology and handicapped people. The agencies and programs providing funding for the purchase of sensory and communicative aids have been terminated or their budgets have been severely reduced. As a result, our U.S. sales of Optacons have dropped 65% since 1979. Today, of all the Optacons manufactured, only 22% are destined for the U.S. -- the remaining 78% are sold outside the U.S. This is a drastic change from the period 1971 to 1980 in which 70% of the Optacons manufactured were sold within the U.S. This reduction in U.S. application of technology for handicapped individuals is a direct result of severe reductions in U.S government social service programs without the establishment of adequate replacement funding sources. We believe the result is a large and tragic unmet need in the U.S. which has harmed all parties involved -- handicapped individuals, government, and society in general.

Weaknesses in the system for diffusion of technology for the handicapped existed even before the budget cuts. In our view the major weaknesses are:

- Drastic state-to-state variations in technology diffusion policies
  For example, in some states provision of an Optacon when employment would result was relatively straight forward prior to 1981, while other states have yet to provide their first Optacon to a rehabilitation client. We have known of cases in which a blind person has moved from one state to another in order to obtain needed rehabilitation technology.
- Excessive bureaucracy and overhead in the delivery system
  Unclear policies and procedures with the requirement of multiple approval levels produce excessive delays and barriers which discourage all but the most persistent. Funding is often provided in an inconsistent, arbitrary manner rather than in accordance with clear policies.
- There are gaps in the system which leave out segments of the handicapped population for no logical reason
  Often it is impossible for a college student to obtain a sensory aid which would be of enormous help in preparing for his vocation. Since sensory and communication aids are not covered by Medicare and Medicaid because they are not considered "medically necessary", there is little or no hope for large segments of the handicapped population to obtain funding for an aid. Only if you are a veteran, or if you are unemployed and an aid is necessary for employment and you live in the right state, there is a chance for provision of the needed technology.

When these system weaknesses were coupled with the subsequent budget cuts, an already defective system was rendered largely inoperative, even though many of the administrative costs continued. In addition, great market uncertainty was created in the private sector which discouraged investment and innovation.

To correct this situation I believe that the most important action that can be taken is to create a market for technology for handicapped people. This will increase the probability that technologies will reach the people who need and desire them, the number one issue discussed in the OTA report. By creating such a market, normal economic forces will produce the most effective technology and delivery systems without excessive bureaucracy and administration. The federal government should play a key role in creating this market because numerous studies have shown that the application of technology by handicapped people is cost effective in savings to federally funded welfare and income maintenance programs. The most effective way the federal government can create a market is by enabling disabled people, or their parents, to have the purchasing power necessary for the aids. This involves the consumers directly in the delivery system process, the second issue discussed in the OTA report.

Thus we recommend that the federal government undertake a cost sharing approach with disabled individuals, or their parents, through a federal income tax credit for sensory and communicative aid expenses for handicapped individuals. We believe this approach would, in the long run, result in a net positive return to the federal government as an increasing number of handicapped individuals lead more productive and independent lives with less dependence on government subsidies.

We also recommend that the Social Security Act be amended to treat sensory and communicative aids as medical equipment and prosthetic devices so that Medicare/Medicaid can cover personal use sensory aids for severe and profound loss individuals.

These two recommendations, tax credits for sensory and communication aid expenses and Medicare/Medicaid reimbursement policy, if enacted, can create a market which would lead to an effective and efficient system for delivery of appropriate technology to handicapped people. This market would then justify and provide the impetus for addressing the remaining key issues and options identified in the OTA report: R&D, trained personnel, evaluation, and financing barriers.

Mr. **Walgren**. Our next witness is Barry Romich.

[The biographical sketch of Mr. Romich follows:]

CURRICULUM VITAE

BARRY A. ROMICH

Current Position

PRESIDENT
Prentke Romich Company (Est. in 1966)
R.D. 2, Box 191
Shreve, Ohio 44676
(216) 567-2906

Education

Case Institute of Technology
B.S. (Engineering) 1967

Registration

Registered Professional Engineer in Ohio
Registration Number 36345

Employment History

1970-1973	Private Consultation
1967-1970	Staff Engineer in the Medical Engineering Research Program - Case Western Reserve University (Cleveland, Ohio)

Personal Data

Home telephone: (216) 567-2961
Social Security: 280-046-8802

Specialty Areas

1. Rehabilitation engineering, consulting and client assessments
2. Design and modification of electronic aids for the severely handicapped
3. ELECTRONIC AIDS SEMINARS

Other Interests

Private pilot, pursuing instrument rating.

PRC
PRENTKE ROMICH COMPANY R.D.2, Box191 Shreve, Ohio 44676 PH(216) 567-2906

Mr. ROMICH. Before I share my thoughts on this OTA report, I think you should know the source of these thoughts.

Our business was formed in 1966 to fill a need. That was a long time ago in terms of technology and handicapped people. For 9 years, it was an evening and weekend activity, a basement operation.

Today, we are still a small business, but we are growing rapidly, and we have had positive impact on the lives of many people. We are working in two basic areas.

One is communications systems for nonspeaking people, and the other is environmental control systems to permit people to be able to have control over various electrical devices in their surroundings.

Our corporate goal is providing appropriate electronic devices and services to the severely physically handicapped in a cost-effective manner.

We have seen over many years inappropriate applications of technology, and we want to avoid that. Cost effectiveness also is important, and we are compromising in the middle—between custom devices for individuals and mass market items that don't serve anyone very well.

The bottom line we are all concerned about here is individuals, individual people. I am coming from that bottom line.

I appreciate the opportunity to be here and to convey some of my views on this. My overall impression of the report on technology and handicapped people is a positive one.

I think it covers every issue in this area. I hope I can think of it come April 15.

The recommendations that I see in the report are really the issues brought up. I see our role as keying in on those particular issues that need action.

The production marketing and diffusion of technologies are typically private-sector activities, and I am considering them as such in my response.

The primary requirement necessary for private enterprise to survive and indeed thrive in our society is a viable market for product and services offered. Other issues are minor in comparison. What are the elements of a viable market? Need, awareness, and funding.

In many areas of the rehabilitation field, the market is simply too small. The market is small, not because the need is small, but because too frequently people needing devices and services do not have, and cannot find, the necessary funding, or do not know that technology can help them.

We have heard many people today indicate that there is a need for what we are doing, so I am not going to discuss that further.

What can be done to enlarge the market of technology for handicapped people? The primary issues I have identified are, first, funding, and, second, education.

We need a comprehensive and equitable funding system, one that serves everyone and does not have to depend on bake sales and bingo, a system with priorities that bear some resemblance to human need.

If I could not talk, and I could not walk, I would need two things. I would need a communications system, and I would need a mobility aid, a way to get around.

The system that exists today is very eager to provide me with a power wheelchair, but that is a much lower priority to me than a communications system.

First, I want to be able to communicate. After that, I can worry about getting around. If I can communicate, I can get anything I want. If I can move from one place to another, that is perhaps all I can do.

Not only does the present lack of adequate funding discourage private enterprise, but we frequently see valuable engineering and rehabilitation professional time being used to pursue the small amount of funding that is available.

We are not making the best use of our resources in this country. Engineers are not engineering; therapists are not providing therapy; teachers are not teaching. They are all trying to come up with some easy way or some possible way to get technology to the people who need it.

Although I represent a company that manufactures technical aids, I recognize that devices alone are not solutions. Many services also need to be funded, including client evaluation, aid selections and application, training and followup.

Possible action can be in two areas. Currently, many programs exist with the goal of addressing the needs of this population. Too frequently, however, those programs either do not cover the provision of technology as a matter of policy, or change so slowly that new technology is not recognized for years after becoming available.

Existing programs need to be reviewed and improved in that area.

There appear to be certain population groups that are not covered by existing programs, although their needs are no different than groups that are covered. Programs are needed to make it easier for these people to have access to technology. If, as is too often the case, personal financing is the only recourse, the burden could be eased through income tax credits, dependent deductions, and other tax incentives.

The other element of a viable market is awareness. Both consumers and rehabilitation professionals need to be aware of the availability and efficacy of technology in this field. The marketing efforts of private enterprise certainly work toward building awareness. However, many rehabilitation professionals are practicing without knowledge of technology and few higher education programs require or even offer courses on technology.

Certification of rehabilitation professionals and education programs should include consideration for technology.

I am talking about the rehabilitation professional educational programs, occupational therapy, physical therapy, speech.

In summary, it is my contention that many of the current problems that exist in the areas of production, marketing, and diffusion of technologies for handicapped people can be solved through the creation and expansion of rehabilitation technology markets. Two primary elements needing attention are: (1) Funding of technologies, and (2) awareness of technologies.

With a market for devices and services, the private enterprise system will see that they are produced, marketed and applied.

Thank you.

[The prepared statement of Mr. Romich follows:]

Views on"Technology and Handicapped People"

My overall impression of "Technology and Handicapped People" is that it is a thorough and comprehensive report covering nearly every issue in this area. The issues cover a wide range of significance. The goal of this testimony, as I preceive it,is to identify those issues that have the greatest influence on this area and to make recommendations for action. These recommendations would then be used by public and private agencies in making policy decisions.

My response will focus on Issue 1: Production, Marketing and Diffusion of Technologies. These are typically private sector activities and are considered as such for this response.

The primary requirement necessary for private enterprise to survive and indeed thrive in our society is a viable market for product and services offered. Other issues are minor in comparison. What are the elements of a viable market? Need, awareness, and funding.

In many areas of the rehabilitation field, the market is simply too small. The market is small, not because the need is small, but because too frequently people needing devices and services do not have and cannot find the necessary funding or do not know that technology can help them.

What can be done to enlarge the market of technology for handicapped people? The primary issues I have identified are first, funding; and second, education.

We need a comprehensive and equitable funding system; one that serves everyone and does not have to depend on bake sales and bingo, a system with priorities that bear some resemblance to human need. Not only does the present lack of adequate funding discourage private enterprise, but we frequently see valuable engineering and rehabilitation professional time being used to pursue the small amount of funding that does exist. We are not making the best use of available resources.

Although I represent a company that manufactures technical aids, I recognize that devices alone are not solutions. Many services also need to be funded, including client evaluation, aid selection and application,training and follow-up.

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1. Funding of technologies and
2. Awareness of technologies.

With a market for devices and services, the private enterprise system will see that they are produced, marketed and applied.

Barry A. Romich
09-24-82

Mr. WALGREN. The need for a market to make these things happen implies the ability to purchase.

Is it your feeling that if a tax credit is created for disabled individuals to purchase technology that there is enough income in this area of our society to take advantage of a tax credit per se? A tax credit implies that one is going to be paying taxes, and that there is an income to create that obligation in the first place.

Is there enough leverage from a tax credit alone to make a number of things that need to happen, happen?

Dr. BLISS. Could I respond to that?

Mr. WALGREN. Yes.

Dr. BLISS. I believe that while a tax credit does not answer all problems, and there would still be problems remaining, a tax credit can go a long way toward a solution and improvement of an existing situation.

I believe that in many cases the technology can improve the income situation of a person and a tax credit, particularly that can be spread over 3 to 5 years to purchase equipment, will create in the field, either through foundations or the private sector, loan funds that will enable the person to use the tax credit to purchase equipment and pay back the loan funds later out of the tax credits, because of the enhanced employment possibility. And particularly in the cases that we see relating to an earlier comment that you made about your concern of rehabilitating disabled people, for what?

Many of the disabled people we work with, those with severe communication and sensory loss, are in great demand in the work force, given appropriate technological aids, and this is the field of the work force where there is currently a scarcity of qualified workers, such as the computer industry, and people who need to work with information from computers.

However, what I am more concerned with, and what I think is even a greater problem, is large Government R&D programs and evaluation programs without the creation of a market. When you say, "For what?", I think this is an analogous problem. When you take these R&D steps and a mechanism for creating a market does not exist, the R&D is for what purpose? I think a tax credit can be a major step for creating a market in a way that is naturally controlled without a lot of excessive bureaucracy and administration, because it is controlled by the income process. The R&D process, I believe, will greatly benefit from this market.

Mr. WALGREN. It would seem that if you were to treat disabled individuals' expenses that are necessary to work as an expense of doing business, if you were to treat them as a small business by themselves, they would then not recognize any of that expense on their income tax. That would be, I guess, a deduction, wouldn't it? It wouldn't really be a credit, but it would be a deduction.

Dr. BLISS. That is right. Currently, in some cases, a business deduction is allowed. In a few cases a medical deduction is allowed, and that has the disadvantage of a threshold, besides being a deduction. But a credit, I think, is what is really needed, and I think the Federal Government has a large stake in this process, because this kind of investment in an individual by the Federal Government will, in the long run, I believe, reduce the Federal expenditures on such things as income maintenance and support.

I think the justification for the Federal expenditure is really that it helps reduce the income maintenance programs currently in effect.

Ms. LITTLE. I agree with the statement that while there are many individuals who are not in the work force, there are many individuals with disabilities who are in the work force, or could be if they had a small break.

At the present time, according to my CPA, we can't even deduct additional costs of transportation to get to work. Yet a plumber can deduct the cost of his transportation because he has to carry his tools.

These physically handicapped individuals have not received the proper attention from the Internal Revenue Service, and I think it is because the IRS and the Department of Census do not know how many people are out there, and how many people could benefit from some tax relief for the physically handicapped.

Dr. BLISS. A group of us in the field have prepared some draft legislation leading to tax credits which we hope to discuss at the Capitol Conference on the Handicapped in the next few days, out of which we hope there can be some legislation which can be introduced in Congress.

Mr. WALGREN. You indicated that in some framework you are able to deduct certain expenses as business expenses. Is that in the individual tax treatment of IRS?

Dr. BLISS. Yes; depending on a person's employment and the equipment, it is possible to deduct some equipment as a business expense, but this is usually on a case-by-case basis and works in some cases but not in others.

Ms. LITTLE. And it is subject to review.

Dr. BLISS. That is right.

Mr. WALGREN. You mentioned numbers in your presentation that I did not see in your written statement. Some 70 percent of disabled are in what income range?

Dr. BLISS. I was quoting from the OTA report, on page 101, which states that 60 percent of disabled individuals of working age earn incomes at or near the poverty level, and of 15 million disabled Americans between the ages of 16 and 64, more than 7.7 million, which is over half, are out of the labor force because they are unemployed, or by choice.

Mr. WALGREN. If 60 percent earn incomes at or below the poverty level, what does that mean the other 40 percent are doing?

Dr. BLISS. There are some very successful disabled people.

Mr. WALGREN. Would those out of the labor force be in that 40 percent? I wonder what they mean when they say earn? Are they talking about 60 percent of disabled people who, in fact, work?

Dr. BLISS. No; the statement was that 60 percent are at or below the poverty level, which means that of that 60 percent a large fraction do not work.

Mr. WALGREN. It is your interpretation the unemployed would be in that 60 percent?

Dr. BLISS. Yes.

Mr. **Walgren**. Some 40 percent of the disabled are then earning income above the poverty level?

Dr. **Bliss**. That would be my interpretation. I think the reference to that data is a paper by a member of the next panel.

Mr. **Walgren**. You mentioned the census data, Ms. Little. What is the status of the census data? Do we know exactly what income ranges are related to what disabilities?

Ms. **Little**. I think it is a little worse than that. As far as I know, the U.S. Census Bureau does not record disabilities. Am I correct in that, Dr. Spencer? The U.S. Census Bureau does not record?

We do not know how many disabilities. We have no demographics on disabilities. We find this constantly in the marketing area. It is very, very difficult to get any reliable information on how many disabled people there are, what type disabilities they have. They just handed me some demographic information. But this is not recorded by the U.S. Census Bureau.

Mr. **Walgren**. I certainly appreciate that testimony very much. I would hope that we could make progress on some tax credits for those with disabilities.

We know they have extremely high expenses, and yet we don't seem to be able to get the IRS to be willing to draw lines.

Thank you very much. We appreciate your testimony.

STATEMENTS OF FRANK BOWE, FRANK BOWE ASSOCIATES, INC., LAWRENCE, N.Y., AND JUDY HEUMANN, CALIFORNIA DEPARTMENT OF REHABILITATION, SACRAMENTO, CALIF.

Mr. **Walgren**. Your written statements will be made a part of the record, and please feel free to elaborate on them or diverge from them.

We will start with Dr. Bowe.

[The biographical sketch of Dr. Bowe follows:]

BIOGRAPHICAL SKETCH

Frank Bowe is founder and chief executive officer of FBA Inc., a management consulting firm located in Cedarhurst, Long Island, New York. His company provides management training, personnel policy, and public relations services to corporations ranging from AT&T to Xerox.

From 1976 to 1981, Dr. Bowe was the first CEO of "the handicapped lobby," the American Coalition of Citizens with Disabilities (ACCD). During his tenure at this organization, major advances in education, rehabilitation, housing, transportation, social security, and civil rights were achieved on behalf of the nation's 36 million disabled and 24 million elderly citizens. Prior to his work at ACCD, Dr. Bowe was a research scientist at New York University for five years, specializing in communication disorders research and training. He has also been a classroom teacher, a public school program coordinator, and a research assistant in what was then DHEW.

Among his community service activities are: US Representative to the United Nations for planning the 1981 International Year of Disabled Persons; consultant to the United Nations in follow-up work after IYDP; consultant to the US House of Representatives Committee on Science and Technology on drafting the framework for legislation (PL 95-602) establishing the National Institute on Handicapped Research and the National Council on the Handicapped; Board of Directors, US Council on IYDP; member of the Intergovernmental Advisory Council on Education; and member of the advisory board for the Office of Technology Assessment's Project on Technology and Handicapped People.

Dr. Bowe received his primary and secondary education in the public schools of Lewisburg, Pennsylvania; his B.A. in English from Western Maryland College; an M.A. in education from the Gallaudet Graduate School, Washington, D.C.; and a Ph.D. in educational psychology from New York University.

He has been awarded an honorary doctorate (LLD) from Gallaudet, a Distinguished Alumni Achievement Award from NYU, and the Catherine Lyle Murray award for achievement in civil rights. He was named to Men of Achievement, a Cambridge, England, biographical publication and as one of the Ten Oustanding Young Men of America by the US Jaycees.

Among his publications are Handicapping America, Rehabilitating America, and Comeback. He recently completed Reasonable Accommodation Handbook for AT&T and a review of the United Nations system for UN/Vienna.

Dr. Bowe lives in Lawrence, New York, with his wife Phyllis and their daughters Doran and Whitney.

Dr. BOWE. Mr. Walgren, thank you for offering me the opportunity to be with you.

You have my statement, which, of course, will be incorporated into the record, so rather than read, I would just comment briefly upon it.

I think, first of all, the development that you have seen in the report and heard about this morning has the potential, quite literally, to just leapfrog whatever it is that a physical disability might be.

It would simply replace whatever it is that was not functioning. Today, we already have very good, small, fairly inexpensive personal computers that will read out loud anything that is programed into them, whether by a blind user or by any other user, where it is being recalled from memory. That will help someone who has a learning disability such as dyslexia, because the person will hear rather than have to read material.

Obviously, it will allow the blind person to keep up with the paperwork. Some of these machines read out loud so fast that it is approximately two to three times as fast as I am speaking now. This means for all intents and purposes that for a blind person to keep up with paperwork, it is going to become tremendously much easier in the next 2 or 3 years than it has ever been.

We have the technology now being tested in a number of different companies that would do the exact opposite. They will enable someone like myself to attend a political rally, for example, and to read off what the machine is hearing while the machine is hearing it.

Quite literally, it will put an instantaneous printed transcript of spoken speech before me so that I could for the first time in my life hear a politician lie to me.

Let me tell you, I am looking forward to that day, sir. I will be able to talk with people on the telephone. I will be able to laugh at the right time during a television situation comedy. I will be able to understand people talking to me in a meeting room without having to depend on that incredible piece of technological equipment who is standing right in front of you now.

The new technology is marvelous. It does not take coffee breaks. It does not talk back to me and does not keep reminding me that I have a Scandinavian accent.

Judy Heumann and I worked very hard for a number of years to try to make transportation accessible for people who are disabled and elderly. We have a long, long way to go.

Some of this technology, however, can enable the severely handicapped person to leapfrog the need to do a great deal of transportation, because right there in the home you can do your shopping, do your banking, read newspapers, and long-distance communication. You can work using distributed data processing when your personal computer has a terminal connection to your home office.

In other words, you would reduce by 90 to 95 percent your need to transport your body from one place to another.

All this we are talking about—whether you are deaf or blind, physically disabled, learning disabled, or whatever—is all emerging out of the same thing—connections between small computers and telephone and other means of communication. This is nothing we could have foreseen 5 or 10 years ago. People talked about it as perhaps happening, but it has happened faster, and the prices have come down much more rapidly than any of us had ever expected.

What all this means, among other things, is that I think we have to look very carefully at that kind of technology and see how we can get it into the hands of people who need it and will be able to use it.

Second, how can we help them to afford this?

Third, how can we make it accessible to them?

Those three basic things—distribution, affordability, and accessibility—have to be met.

How can we do this? We had a series of very exciting meetings a few years ago in your committee, the Committee on Science and Technology. I remember Dr. Spencer, who is a real key man in this kind of work, was here, and we were working with Representative Olin Teague. We talked at that time about the need to coordinate what government was doing so that it would start to make some sense. That was part of the effort that resulted in the National Institute of Handicapped Research, and the National Council on the Handicapped. Those two bodies emerged out of the kind of work we were doing in this committee.

Today, my sense of it is that we will be more effective, looking not quite so much at government as at the private sector.

I have had two or three examples that it might be helpful for the committee to look at.

Judy Heumann can talk more to this issue, because she is from California. In California, they had a program—Pacific Telephone, a part of American Telephone & Telegraph Co.—which is now distributing at no cost devices that will enable deaf people to type on the telephone to each other.

The State is getting its money back over time, because it is getting a lot more money in tax revenues from the use of telecommunications lines. It is also getting revenues from stores, churches, dry cleaners, and people buying these typewriters which connect with the telephone so they can communicate over the State of California.

The State is also getting its money back through a special surcharge, a very small amount of money—I think 18 cents per month—per Californian, for a few years.

Now, the concept I am talking about very simply is that government is saying, we will guarantee the distribution of x-number of pieces of technology. By guaranteeing it, we insure that the price will be low; we assure that the people will get it, and we assure that the means of supply and demand will insure that government will get something back out of all of this. That is a precedent I would like government to look at at the Federal level. It is a precedent for a loan guarantee and large-scale production and distribution at no cost or at low cost.

A second thing worth looking at is the precedent established by the architectural barrier removal program, where, if a business removed a barrier, it was able to get a credit for about $25,000, a tax credit. Later, it was a $100,000 tax credit.

The same precedent, is worth looking at for hardware and software accessibility, so that people can use it.

It makes technology accessible to everybody. Some of the extra cost of making that universally usable might be offset in the form of a tax credit.

Just as we have architectural accessibility, we may need also technological accessibility.

The last example I wanted to offer was that of the targeted jobs credit program, which, of course, you are familiar with. That kind of thing can be worked out. If we would have a company using a piece of technology, so that an individual who was handicapped could perform a job for which that person was trained and qualified, that is a third precedent I would recommend that the committee begin to investigate.

Thank you for being so kind and for putting up with what I know is my difficult-to-understand Swedish accent. You are most kind.

[The prepared statement of Dr. Bowe follows:]

Invited Testimony of Frank Bowe before a joint hearing of
the Senate Committee on Labor and Human Resources and the
House Subcommittee on Science, Research and Technology of
the Committee on Science and Technology on the Office of
Technology Assessment's Report, "Technology and Handicapped
People," 29 September 1982

Good morning. I appreciate this opportunity to meet once again with the Members and staff of these distinguished Committees. Today, as was the case four years ago, close cooperation between the human resources and technology committees of the Congress promises us an exciting opportunity to advance the state of the art in services for persons who are handicapped. While the 1978 legislation, PL 95-602, created governmental bodies to focus and direct federal efforts relating to technology helping handicapped individuals, legislation toward which the hearings this morning may look more likely would serve to target private-sector efforts toward the same goals. It is to this objective that I would like to direct my remarks.

In particular, I would want to see your Committees study carefully the emerging telecommunications technologies such as distributed data processing, teletext, and the like and to ask pointed questions about the role of personal computers in opening employment for persons who are severely disabled. I would think that tax credits and tax incentives possibly may prove more effective in stimulating the work we now need than would more programmatic endeavors such as we saw four years ago.

Today we can see that in the very near future personal computers will do what it is that severely handicapped individuals cannot do. In some cases, the technology already exists. Small computers now read out loud anything appearing on their screens; blind persons are thus able to "keep up with the paperwork" in almost any kind of job. Similar computers now enable persons who face forbidding transportation barriers to work from the home---and to control hundreds of electrical devices at home and at work. Within a few years, speech-recognition software in such computers will enable deaf persons to follow conversations---and to use the telephone with ease. In other words, the personal computer is, in my mind, potentially the single greatest "reasonable accommodation" device ever invented.

We need to make this technology available to people with disabilities, among whom are millions of older Americans.

If we do, they may leave social security and other governmental aid programs for private payrolls. The return to the US Treasury for each such person has been calulated to be some $12,000 per year: about $10,000 not paid in aid and some $2,000 now paid in taxes. Let me stress that: per person per year.

How can we do it? There are many possibilities. I have time to mention three.

First, look at the California experience with telecommunications devices for the deaf (TDD), which the state purchased for free distribution by Pacific Telephone to deaf Californians. The details are in the OTA report. The principle is what is important now: governmental support for technology distribution to disabled people.

Second, look at the architectural barriers removal tax credit. Here, firms get a credit for removing barriers in their buildings. The principle could apply, too, to making technology hardware and software accessible.

Third, look at the targeted jobs tax credit program. Employers hiring hard to place persons, including disabled rehabilitation clients, get a credit for part of the wages they pay these persons in the first two years of employment.

Your two Committees might work with the finance committees of each House of Congress to draft legislation that would provide corporations with incentive to make their technologies accessible---and to hire disabled persons who would use such technologies to do the jobs that need doing. I have mentioned three precedents offering us suggestions on how this might be done. The OTA report, in Chapter 12, which deals with policy options, offers more.

My point: very soon, disabilities will not matter much in employment provided that devices such as personal computers and programs such as distributed data processing and teletext are accessible, available, and affordable to people with disabilities. It will pay us to make them so.

Thank you. I look forward to working with you to develop these exciting possibilities.

Mr. WALGREN. Dr. Bowe, do those targeted tax credits apply to the handicapped at this point? What do we now have in terms of targeted tax credits for the handicapped?

Dr. BOWE. Only for employment. If you are employed in a government-aid program, or if you are a vocational rehabilitation client, and you are hired directly from those government rolls, the Federal Government will allow your employer to have a tax credit equal to half of the first $6,000 they pay you in the first year, and about half of that amount in the second year. That is what we have now—the same thing we have with a number of other targeted minority groups.

It is a precedent that could now be applied to technology; that kind of technology could be used, and the same concept of a tax credit, again targeted, could be used to enhance employment.

Mr. WALGREN. Thank you. I enjoyed your testimony very, very much. Our next witness is Judy Heumann.

Ms. HEUMANN. My name is Judy Heumann, and I would like to thank you for the opportunity to speak before your committee on the financial barriers to technology for persons with disabilities. I am a severely disabled individual, and technology plays an important role in my personal life. However, I continue to have many difficulties in obtaining appropriate technology, and, more significantly, in knowing how I can finance that technology.

I feel these problems are reflected throughout the disabled community irrespective of the age of the individual.

The problems are most severe for a person who is newly disabled and has little or no expertise on who to contact when searching out appropriate technology and how to finance that technology.

I concur with the major conclusion of the OTA report:

> Despite the existence of numerous important problems related to developing technologies, the more serious questions are social ones—of financing, of conflicting and ill-defined goals, of hesitance over the demands of distributive justice, and of isolated and uncoordinated programs.

There are resources that can be used. One example is a self-support plan which is available to meet a one-time cost of equipment purchase. This program, however, is only available to persons who are eligible for SSI or SSDI. I'd like to use myself as an example of how this program works.

When I was a graduate student at the University of California at Berkeley, I had to do a residency in order to obtain my master's degree. I was able to obtain a job working for Senator Williams in Washington, D.C. I was an SSI recipient at that time and was able to take advantage of the self-support plan, which enabled me to save a major portion of my salary toward the purchase of a wheelchair-accessible van, while still receiving SSI benefits. That van, with modifications, cost close to $12,000.

The concept of a self-support plan is excellent; the regulations and restrictions in administering it are a nightmare. Such a plan is rarely utilized because social security and rehabilitation personnel are discouraged by its complexity, and persons with disabilities are frightened by its "once only" limitation.

I will not go into why the self-support plan is so complex, but just say that the development of such a plan usually requires the assistance of a financial benefits adviser, and the only place that these advisers are available are in independent living programs. In many States, rehabilitation counselors are beginning to refer clients to ILP counselors; however, there is limited staff in these programs to handle the need.

The fact that a self-support plan can only be used once is clearly a problem. Again, I will use myself as an example: I am going to need to use an accessible van for the rest of my life; however, although I am now earning a fair salary, I spend a substantial portion of it on my personal care needs. I don't know how I will be able to purchase my next van. The van I purchased in 1979 would now cost $18,000 to $20,000. In another 5 years, God knows how much it will cost.

My wheelchair was purchased while I was on State benefits. By the time I need to buy a new wheelchair, it will probably cost between $8,000 and $10,000. My savings are quite minimal because I have such high personal use expenses.

I don't know what I am going to be doing in the next few years, and I mean this most sincerely, since none of my health insurance will cover any of these purchases. I have not been able to obtain funding to modify my bathroom or kitchen. Inability to make these modifications means I have to spend additional money on attendant care. I personally spend at least $600 per month on attendant care. I am a renter; I am financially unable to purchase a home.

It is more difficult for me to obtain funds for residence modification because those funds are frequently considered to improve the value of the house, or the landlords are unwilling to allow me to modify a house to my own personal needs because the next renter will probably be a nondisabled person.

The problems of a loan guarantee program in my case are considerable: (1) My current salary would disqualify me from a loan guarantee; and (2) even if I was able to obtain a loan guarantee, my salary is insufficient to enable me to pay back the loan. The department of rehabilitation in California has had a loan program of about $300,000, which enables parents to obtain funding to purchase vans with lifts for their disabled children. As of this time, only $55,000 has been loaned out because people cannot meet the economic qualifications which would enable them to pay back the loan.

Since I became disabled in 1949, there have been many significant pieces of Federal and State legislation passed to improve the quality of life for persons with disabilities. Notably, the passage of Public Law 94-142, section 504 of the Rehabilitation Act, and title VII of the Rehabilitation Act, which establishes centers for independent living.

I am a former employee of the Center for Independent Living in Berkeley, Calif., the first such program of its kind in this country. There are currently over 125 similar programs in the United States. One of the goals of these programs is to insure that there is a place where disabled persons can go as often as they need to for assistance in living independently, and in maintaining and changing equipment as their needs and circumstances change.

In the area of technology, this is critical because there is currently no centralized agency which follows a disabled person from birth to death. The Berkeley program had operated a number of services in the area of technology: (1) A wheelchair repair program; (2) a van modification program, which adapted cars and vans to the individual needs of clients; (3) a program where persons who were skilled in inexpensive, affordable technology met with disabled people and went into their homes to help them become aware of what equipment modification and financing was available; (4) a project which evaluated equipment for the VA to determine whether or not, from a consumer point of view, these pieces of equipment were effective.

Of all those services, only the wheelchair repair program remains, due to funding cutbacks. This has had a very significant adverse effect in the disabled community, as there is currently no effective system to work with disabled individuals and technology.

These programs lost their funding largely because the government grants or contracts were short-term and there were no alternative funding sources available. While I do not have documentation to show the number of dollars these programs save by reducing attendant care costs and enabling many individuals to obtain employment, I am quite confident that they are significant.

The Government needs to pay more attention to practicing what it preaches. If you are committed to reducing Government expenditures, you must listen to the suggestions of the disabled community. We do not want to receive handouts, but we do want the services and technology that we need to live independently. Right now, the programs that provide these services are so underfunded that they never have a chance to show the success they could achieve.

Independent living programs, which are run substantially by persons with disabilities epitomize my previous statement. These programs are community-based. They reflect the needs of their constituency. They are trying to service all persons with disabilities irrespective of disabilities. They want to do things as cost-effectively as possible. The creativity and communication in these programs is still not acknowledged. If you visit an independent living program, you will see how technology can be designed cheaply and effectively. These programs have very little money so they have to make a little go a long way. Things don't always look pretty, but they do work.

Disabled people who could serve on government boards and commissions, and who could work with the private sector can be found through these programs. The Government should be acting as a conduit between the community and the private sector to show the private sector that the needs of disabled peoples' needs are an important part of the marketplace.

There are millions of persons with disabilities who could benefit from technology. These individuals need to be able to see and touch equipment to determine what it is they need. They need to be able to assist designers in the development of their products. They need to be able to purchase the equipment once it is known to be beneficial.

There is, quite frankly, no reason to develop elaborate programs to design and display equipment if there is no way to pay for it. I do not believe loan programs will assist persons who are poor. The Government statistics show that the disabled are the poorest of the poor in this country; these people would not be able to pay back the loans. School programs which loan equipment to students are not effective because the equipment stays in school and does not belong to the student when he or she leaves the program.

Let us briefly see who technology should benefit: the disabled child and his or her family. Do not forget that a severely disabled child who is unable to obtain appropriate technology will probably cause additional disability in his or her family.

Again, I will use myself as an example: When I had polio, my parents had already bought a house in Brooklyn, and my father had started a small business. They could not move, but they had enough foresight to know that they were not going to be able to carry me up and down a flight of stairs for many years. They hired a contractor to extend our house by building a bedroom and bathroom.

The only problem was that they did not know who to speak with about what was needed. The result was a bathroom that was intended to allow me to get in and out of the shower myself but has a sink sticking half way in front of the shower. The result was that someone in my family had to lift me, causing physical back problems.

I see this story repeated over and over—parents having to lift their children on and off the toilet, in and out of the bathtub, in and out of a car, up and down stairs. A Stanford Children's Hospital study showed that 94 percent of the care givers had developed back problems.

Now, let us look at the elderly. I am so distressed that the elderly are not benefiting from technology. One of their primary problems is that they do not identify as being disabled.

Well, if they had no disabilities, their needs would not be much different from the nondisabled person. The reality is that the technology which exists is not used widely by elderly persons.

How many of you have mothers and fathers who are now elderly and have problems walking up and down stairs, getting in and out of their homes or bathrooms, walking down the street?

How many of these people have had ramps built into their homes, had lifts installed on stairs, or are using motorized wheelchairs which they could use themselves? How many times have you or a relative said, "I would take Aunt Emily in if I was just younger, but I can't lift any more; I'm not as strong as I used to be?"

Well, brute strength is wonderful, but not many of us have it, and if we do, we don't have it for long. How many millions of dollars could be saved if elderly persons were not forced to see themselves as sick, helpless cripples, but rather as persons who are acquiring disabilities that would have limited effects on their lives if they could benefit from technology?

I am giving all of these examples because I want you to see the adverse impact limited technology is having on our society. There are many things which can be done to ameliorate these problems, but you must have the commitment to change. We hear time and time again that our Government must reduce its budget. In the case of persons with disabilities, unless you kill us, we are in most cases costing the Government money. Why not spend this money wisely so that you at least begin to get some tax return?

I believe that oversight hearings have impact. However, unless you believe that financing is one of the primary problems that exist when looking at the questions of technology, there is really little need to hold any more hearings. If you are interested in learning about alternative funding sources, and, most importantly, if you are interested in putting more dollars into the design, distribution, and purchase of technology, then oversight hearings are an option.

I think, however, you could direct the National Council on the Handicapped to make recommendations. I would recommend that there be persons from the Senate and House serving on such a committee so that the work being done is relevant, and can be used.

We must have a health insurance program which can cover these costs. There must be a way of taking into account additional expenditures that persons with disabilities have when looking at income that makes a person eligible or ineligible for benefits.

In conclusion, I am not an economist, but a consumer and a pragmatist. I know that many of my ideas are correct because I have spent the best part of my life as a disabled person. I know that I am right because I have had disabled friends all my life. I know that I am right because I have been a teacher of disabled children, worked in programs for the elderly, worked in an independent living program. I have seen the suffering that has resulted because of limited technology.

What distresses me is that although technology has advanced, it is not benefiting the people who need it so desperately in order to lead equal lives. We are not asking for luxuries. Technology has allowed many Americans to live more luxurious lives. We are asking for basics: To go to the bathroom by ourselves, to go down a street by ourselves, to get on and off a bus by ourselves, to be able to obtain a job, to be able to live lives free from fear of whether we will have to live in a nursing home, to live free of fear about how we will pay for our next wheelchair, to live free of fear that we have to institutionalize a loved one because we can no longer physically take care of that individual.

There are thousands of us who are ready to give our technical assistance on how to design and distribute technology. But you have the power in this game. If you are ready to spend money, we are here to insure that it is spent wisely. Remember, we want to be taxpayers so we have a vested interest in spending this money with the most frugality and wisdom.

Thank you.

[The prepared statement of Ms. Heumann follows:]

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
and
HOUSE SUBCOMMITTEE ON SCIENCE, RESEARCH AND TECHNOLOGY

JOINT HEARING

September 29, 1982

My name is Judy Heumann and I would like to thank you for the opportunity to speak before your committee on the financial barriers to technology for persons with disabilities. I am a severely disabled individual, and technology plays an important role in my life. However, I have had and continue to have many difficulties in obtaining appropriate technology, and more significantly, in knowing how I can finance that technology. I feel these problems are reflected throughout the disabled community, irrespective of age. The problems are most severe for the person who is newly disabled and has little or no expertise on who to contact when searching out appropriate technology and how to finance that technology.

I concur with the major conclusion of the OTA report: "Despite the existence of numberous important problems related to developing technologies, the more serious questions are social ones--of financing, of conflicting and ill-defined goals, of hesitance over the demands of distributive justice, and of isolated and uncoordinated programs."

There are resources that can be used. One example is a Self-Support Plan which is available to meet a one-time cost of equipment purchase This program, however, is only available to the persons who are eligible for SSI or SSDI. I'd like to use myself as an example of how this program works: When I was a graduate student at the University of California at Berkeley, I had to do a residency in order to obtain my Master's degree. I was able to obtain a job working for Senator Williams in Washington D.C. I was an SSI recipient at that time and was able to take advantage of the Self-Support Plan, which enabled me to save a major portion of my salary towards the purchase of a wheelchair-accessible van, which still receives SSI benefits. That van, with modifications, cost close to $12,000. The concept of a Self-Support Plan is excellent, the regulations and restrictions in administering it are a nightmare. Such a plan is rarely utilized because Social Security and Rehabilitation personnel are discouraged by its complexity and persons with disabilities are frightened by its "once only" limitation.

I will not go into why the Self-Support Plan is so complex but just say that the development of such a plan usually requires the assistance of a financial benefits advisor, and the only place that these advisors are available are in independent living programs. In many states, rehabilitation counselors are beginning to refer clients to ILP counselors, however, there is limited staff in these programs to handle the need.

The fact that a Self-Support Plan can only be used once is clearly a problem. Again I'll use myself as an example: I am going to need to use an accessible van for the rest of my life; however, although I am now earning a fair salary, I spend a substantial portion of it on my personal care needs. I don't know how I will be able to purchase my next van. The van I purchased in 1979 would now cost $18,000 to $20,000. In another five years, God knows how much it will cost. My wheelchair was purchased while I was on State benefits. By the time I need to buy a new wheelchair, it will probably cost between $8,000 and $10,000. My savings are quite minimal because I have such high personal use expenses. I don't know what I am going to be doing in the next few years, and I mean this most sincerely, since none of my health insurance will cover any of these purchases. I have not been able to obtain funding to modify my bathroom or kitchen. Inability to make these modifications means I have to spend additional money on attendant care. I personally spend at least $600 per month on attendant care. I am a renter; I am financially unable to purchase a home, therefore, it is more difficult for me to obtain funds for residence modification because those funds are frequently considered to improve the value of the the house, or the landlords are unwilling to allow me to modify a house to my own personal needs because the next renter will probably be a non-disabled person.

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1. My current salary would disqualify me from a loan guarantee; and
2. Even if I was able to obtain a loan guarantee, my salary is insufficient to enable me to pay back the loan.

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Let us briefly see who technology should benefit: The disabled child and his or her family. Do not forget that a severely disabled child who is unable to obtain appropriate technology will probably cause additional disability in his or her family. Again, I'll use myself as an example: When I had polio, my parents had alrelady bought a house in Brooklyn and my father had started a small business. They could not move but they had enough foresight to know that they were not going to be able to carry me up and down a flight of stairs for many years. They hired a contractor to extend our house by building a bedroom and bathroom. The only problem was that they didn't know who to speak with about what was needed. The result was a bathroom that was intended to allow me to get in and out of the shower myself but has a sink sticking half way in front of the shower. The result was that someone in my family had to lift me, causing physical back problems. I see this story repeated over and over. Parents having to lift their children on and off the toilet, in and out of the bathtub, in and out of a car, up and down stairs. A Stanford Children's Hospital study showed that 94% of the caregivers had developed back problems!

Now let us look at the elderly. I am so distressed that the elderly are not benefitting from technology. One of their primary problems is that they do not identify as being disabled. Well, if they had no disabilities, their needs would not be much different from the non-disabled person. The reality is that the technology which exists is not used widely by elderly persons. How many of you have mothers and fathers who are now elderly and have problems walking up and down stairs, getting in and out of their homes or bathrooms, walking down the street? How many of these people have had ramps built into their homes, had lifts installed on stairs, or are using motorized wheelchairs which they could use themselves? How many times have you or a relative said, "I would take Aunt Emily in if I was just younger, but I can't lift anymore, I'm not as strong as I used to be?" Well, brute strength is wonderful but not many of us have it and if we do, we don't have it for long. How many millions of dollars could be saved if elderly persons weren't forced to see themselves as sick, helpless cripples but rather as persons who are acquiring disabilities that would have limited effects on their lives if they could benefit from technology?

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There are thousands of us who are ready to give our technical assistance on how to design and distribute technology. But you have the power in this game. If you are ready to spend money, we are here to insure that it is spent wisely. Remember, we want to be tax payers so we have a vested interest in spending this money with the most frugality and wisdom. Thank you.

Mr. **Walgren.** I think that testimony speaks more eloquently than any comment from this side could. I would like to add that I think the system of government we have can work and it can be responsive. The handicapped community should be encouraged to push the Government in the right direction.

The greatest motivator that I have seen in the time that I have been here in Congress has been the human instinct to live up to the expectation that others have of you. I know I feel that way, and I think that almost to a person, people in the Congress are driven by that instinct. The challenge is to maximize that leverage and that force in our society.

I, for one, want to reassure everyone that their elected officials are available to them. We do want to know people as individuals, and of their needs.

And so I hope that from these hearings we can at least take away the belief that the system is inclined in the right direction, and that that inclination can be increased by the individual efforts that we might bring to it.

Let me again thank you all very much for your testimony at this hearing. We also want to recognize the people who have been signing and orally interpreting.

Thank you all very much.

[Whereupon, at 1 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

APPENDIX

STATEMENT BY DR. WILLIAM BERENBERG *

FOR THE

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

AND

THE HOUSE SUBCOMMITTEE ON SCIENCE RESEARCH AND

TECHNOLOGY OF THE COMMITTEE ON SCIENCE AND TECHNOLOGY

September 9, 1982

Dear Mr. Chairman and Members of the Committee:

I appreciate the opportunity to offer testimony with regard to the report of the Office of Technology Assessment "Technology And Handicapped People". I have been actively devoted to the problem of handicapped people since 1950 and have a deep and abiding interest in the prevention of disability, the treatment and management of disability, research and development of new methods of therapy, as well as in my academic role devoted to teaching physicians, engineers, therapists and a variety of professionals who remain dedicated to the welfare of the approximately forty million Americans faced with a disabling or handicapping conditions. I have had particular interest in the estimated ten million children in the Country who were either born with a handicapping condition or suffered major disability early in life. Although the numbers

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*Professor of Pediatrics, Harvard Medical School, Boston, Mass.
Project Director, Harvard-M.I.T. Rehabilitation Engineering Center
Vice President for Medical Affairs United Cerebral Palsy, Inc.

quoted above may be approximate, they certainly are on approximation of the truth. If one adds to that, the number of parents, siblings and members of the family who share in the anguish and concern of these individuals the total numbers become overwhelming. Certainly the elected members of the Senate and House of Representatives of our Nation must and do share not only in the empathy for these individuals, their families and relatives, but also in the responsibility for assisting them to achieve their maximal potential in life.

The scientists of this Country and the world have made great strides towards preventing and often eliminating many of the causes of major disabling conditions. Poliomyolitis has been all but eradicated. In the 1940's approximately one-third of the one million individuals suffering from Cerebral Palsy suffered this disability because of incompatibilities in the Rh blood grouping. Approximately one patient in every thousand who suffered from measles, also endured brain damage from measles encephalitis -- although this incidence may seem small when one computes the hundreds of thousands of cases of measles per year, the total number of disabled individuals added to the pool of handicapped individuals becomes numerically of major importance. The last major epidemic of German Measles resulted in approximately thirty seven thousand seriously disabled individuals in a single year (the offspring of mothers afflicted with German Measles during pregnancy) plus the tragic number of miscarriages associated with that epidemic. Medical science has all but eradicated all of these conditions. Today a single case of such a medical catastrophe should herald a sentinel event which should not have occured.

Despite these advances and many more the incidence of handicapping conditions and the total number of individuals disabled is increasing even in the face of the eradication of such previously common causes for disability. The improvement in longevity has added to the numbers of disabled individuals. Medical science's improvement in reduction in mortality of many diseases such as meningitis, brain tumor, shock, stroke, head injury, deaths due to prematurity and a host of other advances has dramatically reduced deaths due to a large number of conditions, but all too often we still fall short of a total cure and remain left with those for whom all efforts have succeeded in maintaining life, but present us with a large group of individuals who suffer from longterm disability. I have little problem in dealing with the ethical issues since I am of the conviction that research, training and care must move on to the next phase which needs to be devoted to further prevention, improved treatment and the ultimate goal of improving care so that this increasing number will be diminished. Meanwhile we must not turn our back on those currently disabled who are with us today and bend every possible effort towards applying the high technology currently available towards converting a disabled individual to a productive, meaningful, useful and satisfying life.

Even if one was so hardened as to disregard the melancholy despair and frustration of the afflicted individuals it would be the fiscal folly to continue the current cost of disability payments through Federal support, Social Security payments, private enterprise pension, and the expenditures by voluntary health agencies, state and municiple programs when the potential now exists to bring these handicapped individuals back into the mainstream of American life and to enable them to achieve gainful employment. Such an accomplishment not only would work to the advantage of the individual, but would remove him or her from the category of recipient of financial aid to that of a self sufficient, taxpaying member of our society.

The National Institute of Handicapped Research (N.I.H.R.) has been established as the lead agency through its efforts on behalf of research for the handicapped. I hardly need to remind any member of your distinguished committees that we are in the midst of an explosion of knowledge in high technology. The Congress of the United States, in its wisdom, in the Rehabilitation Act of 1973 recognized this potential when it established the program for a national network of Rehabilitation Engineering Centers. That program along with its collaboration with other government agencies has been eminently successful in its efforts towards achieving the goals defined in the Rehabilitation Act of 1973. Progress has been held back from its maximal potential by inadequate, short sighted funding. The leadership exists within current Federal administration and scientists committed to the field to make rapid strides. The obstacles can and should be overcome through numerous channels. The Office of Technology Assessment in its report on "Technology and Handicapped People" has appropriately raised multiple issues and provided significant options to many of them. Certainly there is an extreme need for the training of increased numbers of professionals (physicians, rehabilitation engineers and allied health professionals). These individuals need to be exposed to the problems facing the field early in the course of their career in order to develop a particular interest and expertise in the application of technology for the handicapped. The individual professionals currently working in the area are too often totally unaware of what is currently available. Young people entering the field often receive their total training without any exposure to the potential of high technology towards solving the unanswered problems.

There needs to be increased support for demonstration projects to educate the large number of professionals currently unaware of the state of the art.

As an academician in a major medical school I can assure you that too many medical students graduate with only minor exposure to the management of so many disabling diseases. Industry has been understandably successful in attracting engineers into their own fields of interest - engineers who if properly instructed and exposed to the needs of the handicapped might well have been attracted into the field of technology for the handicapped, if proper demonstration programs and curriculum was provided. Physcians, rehabilitation engineers, therapists and health professionals must communicate with each other and develop educational programs designed to promote not only the cross fertilization necessary for research and development, but also critical to the broadening of their educational experience and training. I cannot speak for all voluntary health agencies, but as the Vice President for Medical Affairs for United Cerebral Palsy, Inc., I can assure you that that organization has been a vigorous proponent and at the forefront of supporting efforts to interest and train professionals in the field of Rehabilitation Engineering as well as a significant financial supporter of research in the area.

I do not believe that the task can or should be done entirely by the Federal government, but without the government providing increased support and the continued leadership role, I fear that the potential success may escape us. The brain power exists, the need is overwhelming, the vehicles are in place, but it will require your support, the education of the professionals, the disemination of information, the education of professionals at all levels and the collaboration of educational institutions and universities throughout the Country to achieve what can and must be done.

Those interested in Rehabilitation Research must be educated in such a fashion that they can apply, utilize and develop the high technology now at our command towards achieving the avowed goal of prevention of disability, rehabilitation of the handicapped and an improvement in the lifestyle of so many millions of Americans through attracting the appropriate personnel, training them in an improved fashion both in the areas of application of technology as well as research for improved methods of prevention and treatment.

CURRICULUM VITAE

Name:	William Berenberg, M.D.
Address:	300 Longwood Avenue, Boston, Mass. 02115
Date of Birth:	October 29, 1915
Place of Birth:	Haverhill, Mass.

Education:

1936 B.A.	Harvard College
1940 M.D.	Boston University School of Medicine

Postdoctoral Training:
Internship and Residencies:

1940-1941	Intern, Brockton Hospital, Brockton, Massachusetts
1941-1942	Pathology Intern, Children's Hospital, Boston, Massachusetts
1942-1943	Medical Intern, Children's Hospital, Boston, Massachusetts
1943-1944	Medical Assistant Resident, Children's Hospital, Boston, Massachuset'
1944-1945	Medical Chief Resident, Children's Hospital, Boston, Massachusetts

Research Fellowships:

1936-1937	Fellow, Department of Biochemistry, Harvard Medical School

Licensure and Certification:

1943	National Board of Medical Examiners
1943	Massachusetts License Registration
1945	American Board of Pediatrics

Academic Appointments:

1943-1944	Assistant in Pediatrics, Harvard Medical School
1944-1951	Instructor in Pediatrics, Harvard Medical School
1951-1957	Clinical Associate in Pediatrics, Harvard Medical School
1957-1963	Assistant Clinical Professor in Pediatrics, Harvard Medical School
1963-1966	Associate Clinical Professor of Pediatrics, Harvard Medical School
1967-1971	Clinical Professor of Pediatrics, Harvard Medical School
1971-	Professor of Pediatrics, Harvard Medical School
1979-	Professor of Pediatrics, Harvard-M.I.T. Division of Health Sciences and Technology

Hospital Appointments:

1944-1945	Junior Attending Physician, Children's Hospital, Boston, Mass.
1945-1950	Associate Physician, Children's Hospital, Boston, Mass.
1950-1962	Physician, Children's Hospital, Boston, Mass.
1952-	Chief, Cerebral Palsy Division, Children's Hospital, Boston, Mass.
1954-1957	Chief, Children's Medical Division, Children's Hospital Medical Center, Boston, Mass.
1962-	Senior Associate in Medicine, Children's Hospital Medical Center Boston, Mass.
1968-1974	Chief, In-Patient Medical Servies and Chief, Infants and Children's Medical Services, Children's Hospital Medical Center, Boston, Mass.
1969-1974	Acting Interim Chief of Neonatology; Chief of Oncology, Children's Hospital Medical Center, Boston, Mass.
1969-1974	Associate Physician-in-Chief, Children's Hospital Medical Center Boston, Mass.

Other Professional Positions and Major Visiting Appointments:

Chairman, National Medical and Scientific Committee, United Cerebral Palsy
National Vice-President for Medical Affairs, United Cerebral Palsy
Board of Directors, Research and Educational Foundation, United Cerebral Palsy
Chairman, Research Council, United Cerebral Palsy
Chairman, Professional Advisory Committee, United Cerebral Palsy of Metropolitan Boston
Special Member of the World Commission for Cerebral Palsy
Advisory Committee, Massachusetts Association for Retarded Children
Professional Advisory Committee, Boston Association for Occupational Therapy
Professional Advisory Committee, Association for Aid to Spastic Children
Board of Directors, Society for Prevention of Cruelty to Children
Executive Committee, Governor's Citizens Committee on Children and Youth, Massachusetts
Advisory Committee, Division of Maternal and Child Health, Department of Public Health, Commonwealth of Massachusetts
Committee for Quality of Care, National Center for Health Statistic

Consultant Positions:

1955-	Consultant in Pediatrics to Brockton Hospital
1957-	Consultant in Pediatrics to Massachusetts General Hospital
1964-	Consultant in Pediatrics to Cape Cod Hospital
1967-	Consultant in Pediatrics to Beth Israel Hospital

Consultant Positions (continued):

1955-	Consultant in Pediatrics to Whidden Memorial Hospital
1964-	Consultant in Pediatrics, William W. Backus Hospital, Norwich Connecticut
1962-	Consultant in Cerebral Palsy, Lakeville State Hospital, Middleboro, Mass.
1970-	Consultant in Pediatrics, Children's Cancer Research Foundation
1973-	Consultant in Pediatrics, Malden Hospital
1974-	Consultant in Pediatrics, Falmouth Hospital, Falmouth, Massachusetts
1974-	Honarary Physician, North Shore Children's Hospital
1975-	Consultant to the Bureau of Vital Statistics
1976-	Consultant to the Rehabilitation Services Administration of H.E.W.
1979-	Consultant to the I.H. Schwartz Children's Rehabilitation Center New Bedford, Massachusetts
1979-	Consultant in Pediatrics to the United States Virgin Islands
1979-	Mailman Center for Developmental Disabilities, University of Miami Medical School - Advisory Council

Awards and Honors:

1950	Jacobi Award of the American Medical Association for Research in Pediatrics
1959	Distinguished Service Award, United Cerebral Palsy Association
1960	Distinguished Service Award of the National Society for Crippled Children and Adults (The Easter Seal Society) at Eighth World Congress of the International Society for the Welfare of Cripples
1965	Humanitarian Award, Knights of Pythias
1969	Weinstein Award, United Cerebral Palsy
1970	Presidential Gold Medal Award, Government of Ecuador
1970	Honorary Ph.D. Catholic University, Guayaquil, Ecuador
1978	Distinguished Service Award, Children's Hospital Medical Center
1980	Charles A. Janeway Award, Children's Hospital Medical Center
1980	Alpha Omega Alpha (Honarary)
1982	Distinguished Alumnus Award, Boston University School of Medicine

Major Committee Assignments: See Other Professional Positions

Memberships, Offices and Committee Assignments in Professional Societies:

American Pediatric Society
Society for Pediatric Research
American Board of Pediatrics
American Academy of Pediatrics
State Chairman, American Academy of Pediatrics
American Academy of Neurology
American Academy for Cerebral Palsy

Memberships, Offices and Committee Assignments in Professional Societies (continued):

President, American Academy for Cerebral Palsy - 1969
Chairman, Committee on Education, American Academy for Cerebral Pals
Committee on Handicapped Children, American Academy of Pediatrics
New England Pediatric Society
President, New England Pediatric Society - 1968
Massachusetts Medical Society
American Trudeau Society
Rehabilitation Engineering Society of North America
Society for Developmental Pediatrics
International Cerebral Palsy Society
Council, Mailman Center, University of Miami Medical School
Trustee, Sidney Farber Cancer Institute

Major Research Interests:

1. Handicapped Children
2. Quantification of Spasticity
3. Rehabilitation Engineering

Teaching Experience:

1943-	Clerkship in Pediatrics for Harvard Medical School at Children's Hospital Medical Center (course developer, course participant and attending physician)
1945-	Teaching of residents at Children's Hospital Medical Center
1952-	Co-Director and lecturer, Boston University School of Education annual course, Handicapped Children
	Numerous annual lectures in multiple hospitals throughout the count
1952-1982	Annual participant in seminars and teaching courses for the American Academy for Cerebral Palsy and Developmental Medicine
1965-	Postgraduate teaching - participant in postgraduate course in pediatrics given annually by the Children's Hospital Medical Center
1978-	Program Director for teaching as well as research, Harvard-M.I.T. Rehabilitation Engineering Center

Teaching Awards:

1980	Charles A. Janeway Award, Children's Hospital Medical Center for Excellence in Clinical Teaching

Principal Clinical and Hospital Service Responsibilities:

1. Senior Associate in Medicine, Children's Hospital Medical Center
2. Director, Cerebral Palsy Unit, Division of Handicapped Children
3. Project Director, Rehabilitation Engineering Center, Children's Hospital Medical Cen
4. Chairman, Joint Conference Committee, Sidney Farber Cancer Institute
5. Committee on Resources - Harvard Medical School

Major Administrative Responsibilities:

Director of Cerebral Palsy Unit, Children's Hospital Medical Center
Project Director - Harvard-M.I.T. Rehabilitation Engineering Center
a division on HST
Development Committee, Children's Hospital Medical Center
Building Committee, Children's Hospital Medical Center
Chairman, Rehabilitation Committee, Children's Hospital Medical Cent
Interhospital Rehabilitation Committee, Harvard Medical School
Chairman, Committee on Consultation and Appeals, Harvard Medical Sch

A STATEMENT PREPARED FOR A JOINT HEARING

of the

Full Senate Committee on Labor and Human Resources
and
The House Subcommittee on Science, Research and Technology

September 29, 1982

on

The Office of Technology Assessment Report to Congress

TECHNOLOGY AND HANDICAPPED PEOPLE

Tom J. Cowley

Anna C. Hofmann, Research

SENSORY AID TECHNOLOGY TRANSFER TO HANDICAPPED PEOPLE

The issues related to technology transfer to handicapped people are complex. I am in agreement with the key issues and options stated in the OTA Summary report:

- Increasing the probability of reaching people in need
- Encouraging development and delivery of technologies
- Improving funding of R&D activities
- Reducing financial barriers to acquisition of sensory aids
- Insuring adequately trained professional and business personnel in this field.

With these challenges, how should we proceed? I would like to present three areas I believe to be worthy of your consideration:

FIRST: summarize what we are finding to be the key ingredients of personal success among hearing and speech impaired people we serve

SECOND: focus our attention today on what I believe is the central problem of sensory impaired and handicapped people today: *PURCHASING POWER* .... the ability to translate their needs and desires into tangible personal products and services

THIRD: suggest where I believe the answer lies .... developing a solution compatible with the current supply-side policies evolving in Washington by encouraging business and individuals to seek solutions to their problem vs. increased government spending.

Since 1963, PHONIC EAR INC. has been in the business of developing specialized products to serve the needs of severe to profound hearing and speech impaired individuals around the world. Our company pioneered the application of

FM radio transmission systems designed for use in the education of the hearing impaired in the 1970's. These systems allow for clear transmission of the teacher's voice in the educational environments to a wireless auditory trainer worn by the hearing impaired student. These systems have significantly increased the discrimination scores of individuals with all types of hearing losses and led to important increases in their speech development and their ability to be mainstreamed, both in the educational and vocational environments. New teaching techniques combined with FM technology are preparing increased numbers of hearing impaired students to enter the communicating world. In addition, the FCC recently approved the broader usage of FM Systems in auditoriums, concert halls and churches. These are locations where it is difficult for the hearing impaired to utilize hearing aids because of ambient noise and other acoustic problems.

Similarly in 1978, our company began marketing the first hand-held speech synthesizer specifically developed for use by non-oral individuals. The PHONIC MIRROR HandiVoice takes a phonetically based speech chip and through a combination of ROM and RAM memory, prestores certain words and allows the non-speaking users to develop words and sentences with speech output capability.

Our experience in this field indicates success is developed through personal use of a sensory aid. Teaching and training, light weight, miniature electronics, early (often preschool) identification and use, parental love and encouragement, user motivation, realistic expectations of outcome .... all are ingredients for success. But the most important ingredient is *personal use* of a device on a prosthetic basis. All of us are creatures of habit and a disabled person has to cultivate the habit of utilizing his/her particular sensory aid. (A sensory aid helps restore or substitute a lost skill or ability to see, hear, or speak.)

With this background on personal success, let me move to what I believe is the central problem of disabled and handicapped people today .... *PURCHASING POWER.*

Most families with a disabled child or young adult have already faced enormous expenditures for diagnostic work-ups and sought professional help in dealing with their disabled family member. The plight of these families has not been helped by the latest federal tax legislation that has decreased the medical tax deduction possible on the federal tax return, establishing an even higher hurdle for any medical deduction related to disabilities or handicaps.

Today in the U.S., we find less than 5% of our specialty FM and speech synthesizer products are purchased by individuals with their own funds for their own personal use. I estimate 45% of sensory aids are purchased by educational institutions (with already tight budgets and limited resources) for group use so that a child is exposed to just a few hours each day in the classroom to advanced technological devices. But, school equipment generally cannot leave the premises, so this equipment is not available for 24 hour *personal use.* A small portion 15%, of our type of specialized sensory aid equipment is purchased through Medicare/Medicaid, Vocational Rehabilitation, or other third-party reimbursement. The balance, 35%, is purchased by philanthropic organizations and donated to individuals, schools, etc. This has led to a very low market conversion and obviously very high costs of products for these specialized personal needs.

In a number of European nations, governments are purchasing personal sensory aids for qualified indivduals below the age of 35 years. Specifically, I am thinking of what has been general practice in Scandinavian countries for a number of years, i.e., the audiological programs and sensory aids are paid for through personal taxes .... socialized medicine. Also, recent legislation in Italy exists whereby the government pays for a personal sensory aid when a child can be integrated and mainstreamed into regular classrooms. Other European nations provide similar government support.

I hope you will agree with me when I say, the problem in the U.S. is .... *effectively assisting people in need.*

> *HOW CAN WE CREATE BUYING POWER AMONG THESE INDIVIDUALS ON A REASONABLE COST SHARING BASIS SO THAT WE DON'T GET INTO GOVERNMENT GIVE AWAY PROGRAMS?*

I believe the time is at hand for the Federal government to play the role of a *catalyst* in two areas:

- a cost sharing approach with disabled individuals or their parents through Federal tax credits for personal prosthetic rehabilitative devices and services purchased, and
- directives to Medicare/Medicaid reimbursers supporting the "coverage" of personal-use sensory aids as prosthetic devices for severe and profound loss individuals.

WHY FEDERAL vs. STATE LEGISLATION? The Rehabilitation Act of 1973 and Education of the Handicapped Act of 1975 are Federal laws. The needs of the sensory disabled are national in scope. The priority is one that is being sounded across our country. Effectiveness on a state-by-state basis has been fragmentary.

HOW CAN THE FEDERAL GOVERNMENT BE A CATALYST? Tax incentives have effectively been utilized in other areas of national priority, i.e., energy savings, individual retirement savings, and oil/gas exploration. The payback among the disabled through a tax rebate will compound as an increasing number of individuals lead fuller more independent lives, less dependence on government subsidies.

Medicare and Medicaid programs reach a small (probably less than 20%) portion of families of severe and profound users of sensory aids. But Medicare/Medicaid can become the bellwether in setting the pace among other insurance and third-party payers.

These two Federal initiatives, shared tax rebates and Medicare/Medicaid reimbursement policy will increase purchasing power .... *important purchasing power* .... that can then be translated into delivery of tangible products and services. The market expansion will then in turn focus resources on key issues and.options identified in the OTA report: R&D, delivery, financial barriers, trained personnel, industry participation.

In closing, I would like to leave you with these thoughts:

- *PERSONAL SUCCESS* can be achieved among the hearing and speech disabled through *personal use* of a sensory aid
- *PURCHASING POWER* .... is a principal problem among disabled families
- *A SOLUTION* in keeping with the mood in Washington, which is: legislated shared tax credit and stronger initiatives concerning third-party reimbursement coverage of these products.

I believe the time is right! What we are talking about today should be a national priority because we have the opportunity to help a whole generation of sensory disabled individuals to strive to meet their maximum potential.

PHONIC EAR INC.
Mill Valley, CA

Tom J. Cowley
President

Anna C. Hofmann
Market Analyst

CLOSED-CAPTIONED TELEVISION

New Access to Equal Opportunities for Hearing-Handicapped Americans

A Statement for the Record
of the
Capitol Conference on Technology and Handicapped People

by the

National Captioning Institute, Inc.
5203 Leesburg Pike
Falls Church, VA 22041
(703) 998-2400

September 29, 1982

INTRODUCTION

The single most common physical handicap in this country today is impaired hearing. It afflicts at least 16 million Americans of all ages, and the incidence is growing due to industrial noise and other factors. At one end of the spectrum are the truly "deaf" whose isolation from society's mainstream is almost total. At the other end are those children and adults who are traumatized to feel their familiar world slipping away when hearing loss occurs. All, however, belong to a vulnerable population whose members have too often unwillingly ended up as burdens to society rather than as participating citizens. New technology now makes possible for the first time in history a direct attack on this critical area of human need through an innovative program which promises significant benefits of broad availability and applicability.

The unique closed-captioned television service was inaugurated in March 1980 by national broadcasters, both public and commercial. "Closed" captions, invisible unless triggered by a special decoding device, enable viewers to read on the TV screen what they cannot hear. There already is mounting evidence that access to television's abundance of information, culture, and language opens up new educational horizons and new avenues toward equal opportunity and economic independence for a severely disadvantaged minority population, particularly its children and youth.

This singular mainstreaming program is provided through the National Captioning Institute (NCI), a nonprofit and tax-exempt corporation with operations centers on both coasts in close proximity to major TV production houses and network broadcast origination centers. NCI's Board of Directors is composed of recognized leaders in business and television. Advisory boards from the Writer's Guild of America and the nation's hearing-impaired community actively monitor and promote NCI's output. Members of the professional and technical staff are highly qualified and firmly committed. Full cooperation is maintained with established agencies in related fields.

PRESENT STATUS

The national closed-captioned television service has experienced steady growth and further technical development since March 1980. A few highlights in response to the needs most often expressed by hearing-handicapped viewers:

- Regular programming: The number of program hours per week has increased in both volume and variety due to growing participation by other broadcasters, advertisers, and corporate contributors.
- Live and real-time captioning: Virtually instantaneous captioning of national television newscasts, Presidential addresses to the nation, and major sports events has been a significant added forward step. Technical capability for real-time (instant) captioning was first demonstrated during the 1982 Academy Awards ceremonies, and

this new technique will be used to caption network feeds of ABC World News Tonight beginning October 1982 under contract with the Department of Education. For the first time in history, hearing-impaired people have access to the news "while it is still news." Corporate funding now provides real-time captioning of major sports programs and such significant events as the recent Shuttle launch and landing.

- Full-screen "printed radio": The decoder's text setting can provide a wide variety of non-program-related information pages. Already in operation are daily news summaries, special news bulletins, closed captioned program schedules (updated from print listings), and weekend sports scores. A weekly "magazine" specifically for the nation's deaf and hard-of-hearing population will be launched October 1982.
- International outreach: Several other countries are keenly interested in the technical viability of America's closed-captioning system and its unique social responsibility service to hearing-handicapped citizens. Canada officially adopted the system and began to carry captioned American programming in 1981. NCI now is captioning Canadian-produced programs (in both English and French) pending establishment of one or more captioning centers in that country with assistance of NCI's technology and expertise. Electronics engineers in England and Australia have solved the technical problem of broadcast-standards conversion so that captioned American programs can be broadcast there also. These developments and inquiries from around the globe prompted NCI to establish an "International Caption Exchange Program" beginning in 1981 - The International Year of Disabled Persons.

- Home videocassette movies: Three feature films from Columbia Pictures are already on the market, and nine more will be released in October 1982.

FUNDING SOURCES

Funds from the U.S. Department of Education for the start-up of NCI end in 1982. An intrinsic element of NCI's primary goal is to achieve financial self-sufficiency for its closed-captioned television service. NCI's primary source of revenue is client fees for captioning, but these revenues are not yet sufficient to make this single-purpose company financially self-supporting. Closed-captioned television will not be a commercially attractive expenditure for broadcasters until its viewership grows substantially as measured by decoder sales. Toward that end, NCI has mounted an intensive public awareness campaign nationwide. In the interim, the private sector is increasingly making corporate good citizenship investments in this pioneering social mainstreaming program for a severely disadvantaged population.

VIEWER RESPONSE

NCI, the broadcasters, and corporate funders receive thousands of letters attesting to the fact that closed-captioned television has already proved to have extraordinary impact on enriching the lives of this severely disadvantaged population and vastly improving access to equal opportunity in a hearing world. Exemplary of the dramatic upsurge of hope is this quote from the father of a deaf child in Texas:

- *"Our 8-year-old son misses out on so much that the hearing world takes for granted. He will never hear the sound of a symphony, or a sigh of contentment, or the bark of a dog, but now at least he can 'hear' events on television."*

And from another parent in Ohio:

- *"My deaf son . . . has discovered a new dimension in his world. This ability to share TV with his family has dramatically changed his personality and attitude and has greatly improved our family relationship."*

And from a 22-year-old in Missouri:

- *"I thought I had died and gone to heaven.' Captioning can help me develop in a way I've never had opportunity to before."*

And from an educator at the Western Pennsylvania School for the Deaf:

- *"The captions spark our students' interest and reinforce their language. You can't deny the impact of the image and the language together."*

And from another educator of the hearing impaired in California:

- *"The children are getting entertainment and learning words and phrases, too. It's like making castor oil taste good."*

And from a viewer in Maryland who expresses the basic theme of all:

- *"NCI allows us to rejoin the human race, and we can argue our views because we now know what we are talking about. . . . It's hard to believe this is happening in my lifetime."*

THE FUTURE

The nonprofit and tax-exempt National Captioning Institute was established for one specific purpose to open new educational horizons and new avenues toward equal opportunity for hearing-handicapped Americans of all ages through access to this country's most powerful source of information, entertainment, and language -- television. An exemplary coalition of federal and private investment is helping to move the innovative closed-captioned television service to permanence and self-sufficiency amid mounting evidence that the primary goal is being eminently achieved.

Technology, however, often reaches beyond the uses for which it was originally intended. The telephone was invented in an effort to develop a hearing aid. Instead, it opened up communications for the world. Braille was originally intended for military use in the dark. Instead, it expanded communications for the blind. Similarly, closed captioning - specifically developed for television viewers with impaired hearing - can be expected to extend its benefits to a myriad of reading and learning disabilities among the population as a whole.

AMERICAN FOUNDATION FOR THE BLIND, INC.

Statement on Technology to be delivered
to the joint session of the House Committee
on Science and Technology and the Senate
Committee on Labor and Human Resources on
September 28, 1982.

The American Foundation for the Blind takes this opportunity to state for the record its unequivocal endorsement of the use of modern technology where applicable to enhance the educational, rehabilitation, and career pursuits of blind and visually impaired persons, as well as all disabled persons.

From what we have seen thus far, i.e., computerized braille storage and production, optical scanning devices transferring print to tactual representations, speech computer response terminals, electronic travel aids, and a broad range of talking instruments, we believe we have only scratched the surface of the areas in which technology can aid blind and visually impaired persons.

We also firmly believe that government has a vital role to play financing future research and development of technology for disabled persons. We view the disabled population of the United States as a vastly under-utilized national resource. We need only look at those blind and visually impaired persons who in the past, through motivation and self-determination, have created their own success stories without benefit of modern technology, and wonder what they and many others might have accomplished, not only for themselves, but for our country, had today's advances been available to them.

Research and development should be continued and expanded in the following six areas:

15 WEST 16TH STREET NEW YORK N.Y. 10011 / TEL (212) 620-2000
CABLE ADDRESS FOUNDATION NEW YORK/AN EQUAL OPPORTUNITY EMPLOYER

FIELD OFFICES
Region I 15 West 16th Street, New York, New York 10011 (212) 620-2039
Region II 15 West 16th Street, New York, New York 10011 (212) 620-2037
Region III 203 North Wabash Avenue, Chicago, Illinois 60601 (312) 269-0095
Region IV 100 Peachtree Street, Atlanta, Georgia 30303 (404) 525-2303
Region V 1111 West Mockingbird Lane, Dallas, Texas 75247 (214) 630-8035
Region VI 780 Market Street, San Francisco, California 94102 (415) 392-4845
Legislative Office — [illegible] L Street, N.W., Washington, D.C. 20036 (202) [illegible]

THE LEGACY OF HELEN KELLER

Helen Keller inspired millions throughout the world by her triumph over deafness and blindness. She used her personal miracle of communication to open the world for other blind and deaf-blind people. She appeared before legislatures, gave lectures, wrote articles, and above all, made herself an example of what a severely handicapped person can accomplish. When the American Foundation for the Blind was established in 1921, she found in it a national organization that shared her purpose. From 1924 until her death in 1968, Miss Keller was a member of the Foundation staff, serving as counselor on national and international relations. It was also in 1924 that she began her campaign to build an endowment fund for the Foundation. Through this fund and the kindness of present benefactors her work is continued.

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*Blind

1. Technology which enhances independent living, for example, accessibility to blind and visually impaired persons of computerized banking machines, and audio output to video text displays.
2. Employment and business opportunities utilizing a broad range of production and office equipment modified with voice or braille outputs.
3. Development of new optical and electronic devices which maximize utilization of low vision.
4. Devices that enhance communication specifically geared toward the ability to educate blind and visually impaired persons.
5. Creation of new aids to assist blind diabetics in self-care such as talking glucose analyzers and devices for self-administration of more accurate dosages of insulin.
6. A program of basic research and development should be undertaken to apply modern technology in meeting the needs of multiply impaired and older blind and visually impaired persons.

These latter groups, blind diabetics, multiply impaired, and the elderly, represent the most siginficant numbers of blind and visually impaired persons, yet little has been done in the area of applying technology to meet their needs.

Technology can make the difference between blind and visually impaired children being educated on an equal basis with their sighted counterparts or receiving only rudimentary benefits from their educational experiences. Technology can make the difference between an individual with severe visual impairment working in a job setting commensurate with his or her talents, interests, and abilities, or accepting under-employment merely for the sake of having a job. Technology can also make the difference between older visually impaired persons living in their communities independently, or living in costly institutionalized settings, or at best, with greater dependence upon family and friends.

Those who monitor our economy might say that we cannot afford government financing of research and development in the area of technology for disabled people. If we are to continue, however, as a nation preeminent in social, economic and scientific developments, a nation which exerts true leadership in all of these areas, we can ill afford for our government not to finance such programs. The future of the United States demands that we utilize every resource at our disposal. History has shown that governments and nations flourish or decline in direct proporation to the degree in which they are both willing and able to develop and utilize the human potential at their disposal. The United States is no different. As we rapidly approach the 21st century, we cannot afford to leave undeveloped the potential contributions to our future stability of hundreds of thousands of disabled Americans. If we are foolish enough to do that, we can less afford the economic burden of responding to their human needs.

What the American Foundation for the Blind is suggesting in the strongest way we know how is that financing of the development of technology for disabled persons should not be viewed as a reckless expenditure in a runaway budget, but as a necessary investment in a stable future.

Respectfully submitted,

William F. Gallagher

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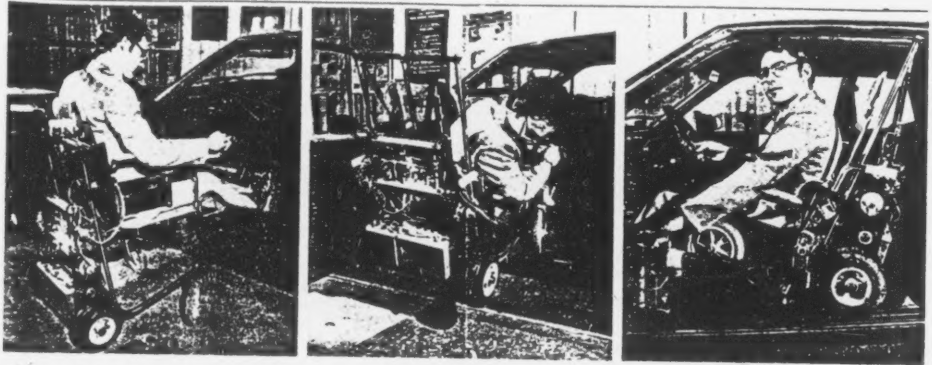
Executive Director

WFG/nm



Photos by Don F. Connolly—Gamma-Liaison

A self-lifting system for drivers: New advances are giving the disabled more control over their environment

Help for the Handicapped

More than 35 million Americans suffer some form of physical or mental handicap. For many, such simple tasks as eating a meal, dialing a telephone or saying hello may be impossible without the aid of others. Disabilities take a toll on the victims, who want more independence, and on their families, who often must cope with the emotional strains and demands of caring for them. Increasingly, engineers and medical researchers are working to lessen that burden, adapting some of today's most sophisticated technologies to create aids for the handicapped. At a recent meeting in Houston, engineers unveiled a wide range of new devices, some now in production and others still at the prototype stage. All have one thing in common: making the handicapped more self-sufficient. "We can't cure the disability," says Dr. William A. Spencer, head of the Institute for Rehabilitation and Research in Houston, "but we can control it."

The most promising devices discussed at a conference of the Rehabilitation Engineering Society of North America are for handicapped people who have lost the use of their limbs. Engineers at the Palo Alto Veterans Administration Center in California have developed an electronically controlled remote robot arm that is combined with a voice-recognition system and a computer. To program the robot, the handicapped person verbally describes the task he wants done by breaking it down into a series of moves, which the arm carries out. Once the instructions are stored in the computer's memory, he gives the task a name. Then he simply says the name of the task and the robot arm will carry it out from start to finish. The robot recognizes and responds only to the voice of the user and must be given new instructions before it can be used by anyone else.

The Palo Alto team is now working to mount the robot on a mobile device—and give it sight. The robot's computer could be programmed to find its way around the user's home, and also carry a small video camera. Watching the robot's progress on a television monitor, the user would give it voice commands, guiding it to go to a bookshelf, for example, and pick out a specific book, or to the refrigerator and bring back a snack. The robot's inventors hope to have it ready for commercial production within five years. "Given the cost of nursing care, the robot should pay for itself in two years," says Robert Smith, a mechanical engineer on the Palo Alto team.

Computer Power: Remember the NASA moon buggy the astronauts used to tour the lunar landscape? Similar technology is being adapted for severely paralyzed drivers. With federal funding, Nelson and Johnson Engineering of Boulder, Colo., has taken an ordinary van and put the steering, accelerating and braking mechanisms into a single "joy stick" mounted to the driver's right.

Robot arm: Voice commands

While some driving systems for the handicapped already exist, the NASA-adapted technology is geared for severely handicapped individuals who have little use of their bodies. The joy stick can easily be manipulated with two fingers. Another device, built at the University of Michigan, eliminates the need for drivers to get in and out of their wheelchairs; the driver is lifted into the car by a specially installed hydraulic suspension system.

Many of these new devices make new use of the power of the computer. Johns Hopkins researchers, who are developing a computer-controlled robot wheelchair arm similar to the one being developed at Palo Alto, are also working on equipment that will put a full-fledged computer at the fingertips of paralyzed users. Instead of having to hit individual keys, operators of the Hopkins system tap out letters in Morse code on a device that can be worked with a chin or a finger; it can even respond to breath controls.

Hope: Computers are being put to a more fundamental use. For many handicapped young children such as those who are severely retarded or have cerebral palsy, the very notion of communication may be foreign. Researchers at the Children's Hospital of Stanford University have developed a flat membrane keyboard with large color pictures of animals printed on it. When the child presses one of the pictures, it is displayed on the computer screen, showing the child that his action can produce a predictable result. In time, as more symbols and words are displayed on the keyboard, the learning process begins. "This teaches children what communication really is," says engineer Hugh O'Neill, "and it gives them some control over their environment." For all the handicapped, technology holds out the hope that someday they will exercise the same control over their environment as everyone else.

DAN SHAPIRO in Houston